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James W. Chavers

*Antioch University Santa Barbara*

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DOUBLE WHAMMY: INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF  
OLDER AFRICAN AMERICANS EXPERIENCING HIV & AGE-RELATED  
COMORBIDITIES

A dissertation presented to the faculty of

ANTIOCH UNIVERSITY SANTA BARBARA

In partial fulfillment of  
the requirements for the  
degree of doctor of

DOCTOR OF PSYCHOLOGY  
in  
CLINICAL PSYCHOLOGY

By

JAMES WESLEY CHAVERS, JR.  
May 2017

DOUBLE WHAMMY: INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF  
OLDER AFRICAN AMERIANS EXPERIENCING HIV & AGE-RELATED CO-  
MORBIDITIES

This dissertation, by James Wesley Chavers, Jr., has been approved by the committee members signed below who recommend that it be accepted by the faculty of Antioch University Santa Barbara in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

Dissertation Committee:

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Dan Schwartz, Ph.D.  
Chairperson

---

Steven Kadin, Ph.D.  
Second Faculty

---

Charles Hilliard, Ph.D.  
External Expert

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### Abstract

HIV among older African Americans represents one of the fastest and largest growing populations of infected groups in America (CDC, 2008). With the availability of anti-retrovirals (ARV), or AIDS cocktail drugs, HIV has become a chronic illness. As African Americans are living longer with HIV, they are encountering the diseases that are consonant with aging. The effect of aging with HIV and an age-related comorbid condition can be physically and emotionally debilitating. Many of these older adults are also dealing with poverty, stigma, poor healthcare access, and limited social support. The purpose of this study was to explore how these older African Americans make sense of their experience of living with HIV and an age-related comorbidity, through semi-structured interviews. Using a form of qualitative analysis called interpretative phenomenological analysis (IPA), this researcher located three superordinate themes or principal areas of concern to older HIV-positive African American adults' understanding of their lived experiences with HIV and age-related co-morbid conditions: "HIV as the new normal," "HIV spurs self-advocacy," and "health as a fragile construct." The results suggest that while older African Americans' current experiences of HIV may be less daunting, their experiences of co-morbid conditions are more acute and severe, and combined with HIV, have left them more vulnerable and in need of support. The electronic version of the dissertation is accessible at the Ohiolink ETD center <http://www.ohiolink.edu/etd>.

*Keywords:* African American, Black, HIV, comorbidities, co-morbid conditions, AIDS, older, older adult

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## **Chapter I: Introduction**

### **Statement of the Problem**

The Center for Disease Control (CDC; 2008) reports that one of the fastest growing populations of people infected by the Human Immunodeficiency Virus (HIV) are persons 50 years and older. By the year 2015 these older adults will comprise 50% of the U.S. population of infected persons (Edward, Bamighausen, & Negin, 2012). This is true of heterosexual adults, particularly women, as well as older gay men (Emlet & Farkas, 2001). In addition, the CDC's accumulated data of recent infections within 37 states between the years 2005 and 2008 revealed that African Americans were by far the highest group to contract HIV (Laffoon, Johnson, Cohen, Xu, & Shouse, 2011). Although African Americans during this time comprised 13% of the United States population, they represented 50% of the infected population (Laffoon et al., 2011). For adults over 50, infection rates were highest among African Americans (CDC, 2008). This number includes long-term survivors and the newly infected. Storholm et al. (2013) assert that with the introduction of anti-retrovirals, we are seeing a "graying of AIDS" in America as infected people are living longer.

However, even as they are living longer, this population is now confronting diseases that typically afflict people in their middle age and older adulthood. For these middle aged adults the specter of living with HIV is compounded by ailments and diseases that are concordant with aging. According to a study by Guaraldi, et al. (2011), the prevalence of multi-morbidities was higher in long-term survivors than in the more recently infected. Both infected groups had higher rates of multi-morbidities than in the

non-infected group of similarly aged-peers. This included higher rates of cardiovascular disease, hypertension, and diabetes. Across the board in measurements of health, mental health status, and socioeconomic status, this crisis is most acutely experienced by HIV+ older adult African Americans (Longmire-Avital, Golub, Parsons, Brennan-Ing, & Karpiak, 2012). Little academic or medical research has been conducted to address the disparity of disproportionately higher rates of HIV among older African Americans and their experiences, compared to all other infected groups (McGinnis, et al., 2003; Storholm, et al., 2013).

### **History of HIV/AIDS in the United States**

To better understand the experiences of a person living with HIV and AIDS, one must have an understanding of the history of HIV and how it has evolved since its discovery (Tan, 2013). In 1981, news media outlets began reporting stories about a cancer that was afflicting young gay men called Gay-Related Immuno Deficiency (GRID). In the years leading up to that diagnosis, people were showing up in hospitals and clinics with Kaposi's Sarcoma, Pneumocystis Pneumonia, and Wasting Syndrome; all symptoms of disorders related to weakened immune systems (Bayer & Oppenheimer, 2000; Fan, Conner, & Villareal, 2000).

Because the symptoms of the disease were most prevalent among young homosexuals, health professionals originally considered it and broadcast it as a gay male disease, hence the diagnosis of GRID (Tan, 2013; Cohen, 2001). As the disease began to appear in non-homosexual populations (i.e., IV drug users, Haitians, and women) however, in June 1984 the scientific community revised its initial findings and relabeled the disease Acquired Immune Deficiency Syndrome (AIDS). The disease AIDS was

“acquired” by infection from a virus contracted through unprotected sexual intercourse of any kind, by contact with infected blood via shared needles and/or transfusions, and by children born to mothers with HIV (Tan, 2013, Cohen, 2001; Fan et al., 2000). The HIV virus specifically attacked the cells of the body’s immune system. The virus invades specialized cells called CD4 or T-cells and makes copies of itself, thus weakening the immune system. When the immune system is sufficiently compromised, it becomes unable to protect the body from illness and opportunistic infection. AIDS is the diagnosis that results from a severely compromised immune system.

The same year the scientific community relabeled it AIDS, a blood test was developed to detect the virus. Designed to screen for the antibodies the body produces to fight HIV, the test was used to screen the blood in blood banks across America (Tan, 2013, Cohen, 2001). Of the approximately 5000 cases of AIDS that the CDC received reports of, almost half of those infected had died (Bayer & Oppenheimer, 2000). The life expectancy for the earliest known HIV patients was 10 years from time of infection (“Time from HIV-1 seroconversion to AIDS,” 2000). The patient would not initially know that he or she was infected, as they would have been asymptomatic (Fan et al., 2000). By the time that a patient began to exhibit symptoms, the virus would have fully invaded the body and crippled the immune system.

Toward the end of the 1980s, the medical community began to develop a treatment that slowed the progression of HIV. Azidothymidine(AZT) and Dideoxycytidine (DDC) are the two drugs that were approved for treatment (Tan, 2013; Fan et al., 2000). However, the manner in which they were prescribed and the drugs’ toxicity and long-term damage to the patients’ bodies, made the treatment almost as

deleterious to the patients' well-being, as the disease itself (Tan, 2013). Infected persons had to take as many as two dozen pills each day for life (Tan, 2013; Fan et al., 2000). As a consequence, the mortality rate was the highest during the 1980s through the middle 1990s. The CDC reported that during that time there were an estimated 641,000 AIDS cases in the United States, of which 60% had died (Fan et al., 2000). AIDS was the leading cause of death in the United States for people aged 25-44 (Tan, 2013).

Besides fear and anxiety, public reaction, at the height of the epidemic included stigmatizing and shaming people who were HIV positive (Tan, 2013). Because the principal method of becoming infected or transmitting the virus was sexual, strong condemnation and blame came from religious and politically conservative sectors of the nation (Tan, 2013). The strongest prejudice was reserved for, and the greatest hostility was directed toward, homosexual men (Tan, 2013; Herek, Capitanio, & Widaman, 2003; Fan et al., 2000). Although AIDS had spread throughout the general population by the late 1990s, it was still seen as a gay disease (Tan, 2013; Fan et al., 2000). So pervasive was the prejudice against homosexuals, religious and cultural conservatives asserted that gay people "deserved" to contract the disease (Herek & Glunt, 1988; Tan, 2013). Gay men and African Americans of all the infected groups continued to have the highest rates of infection and death (CDC, 2008; Tan, 2013). The CDC (2008) remarked that higher infection rates among African Americans correlated with high incidences of poverty, sexually transmitted infections, lack of social support, lack of housing, and low literacy rates

It was not until the middle 1990s, when medical research had introduced anti-retrovirals in the form of highly active antiretroviral therapy (HAART), a medication

regimen of two to three different drug combinations that halted the virus' growth in the body and reversed the damage to the immune system, that a dramatic reduction occurred in AIDS mortalities (Tan, 2013; Fan et al., 2000).

In the 21<sup>st</sup> century, improvements in AIDS treatments in the United States have reduced the epidemic from a life-threatening to a chronic disease (Deeks, Lewin, & Havlir, 2013; Tan, 2013). An increased selection of anti-retroviral drugs and easier access to them, for a larger segment of the population, has helped to continually reduce the mortality rate (Tan, 2013). Nevertheless, HIV remains incurable and current drug regimens require strict adherence (Herring, 2006). A person must take these drugs as prescribed for the rest of his or her life. If an individual neglects to carefully follow the regimen, a break in adherence could spur the virus to mutate and become resistant to the drug. Resistance presages mutated viruses reproducing in the body, overpowering the immune system, and accelerating the onset of AIDS (Herring, 2006; Wensing et. al, 2005).

### **Introducing the phenomena of Aging with HIV and a comorbidity**

For the population of older HIV+ African Americans, poverty, lack of social support, stigma, and low literacy rates are a fact of life that can make strict adherence challenging. Balancing complex disease rituals of the chronic sort like HIV and introducing debilitating life-course diseases such as heart disease, diabetes, and hypertension and their treatment protocols into the mix, has the potential of being overwhelming for this marginalized population (Herring, 2006). It is not unusual for members of this cohort to fall out of care. Death from HIV-related illnesses and

comorbidities due to non-adherence remains highest among African Americans (Marcie, Colen, & Link, 2010; Herring, 2006).

In America as in Africa, as HIV matures into its third decade, scientists and healthcare workers are faced with the reality that infected persons who were not expected to survive now have to negotiate aging with HIV and its attendant comorbidities (Deeks et al., 2013; Mills, Rammohan & Awofeso, 2011).

### **Purpose of the Study**

In 2012, as a facilitator of an older adult HIV survivors group mostly consisting of Anglo members, this researcher became a participant-observer of the struggles that members of the group suffered living with HIV and an age-related disease(s). One member shared how she was afflicted with heart disease, and that the physician informed her because of her compromised immune system, she could not have the surgery that could correct the problem. She was left with the only option of taking medication and closely monitoring her condition until the disease finally claimed her. Her precarious position necessitated interactions with numerous providers such as her primary care doctor, her HIV doctor, and the cardiologist, as well as carefully adhering to complex medication regimens. Another member described how hypertension made it difficult for him to walk. This member had to rely on others to help him make his appointments with his providers. Given the reality of that individual's situation, and others similar to the member's heart condition, this researcher wondered what was it like in the lives of older African Americans similarly afflicted.

In 2014, I conducted practicum training at a local HIV community health clinic that served mostly African American and Spanish-speaking clients. During that training, I

began facilitating an older Adult HIV support group that was almost exclusively African American. All of the clients with whom I interacted were indigent and relying on the HIV clinic for basic life services. Almost all were living with a co-morbid condition, had a history of or were currently struggling with substance abuse, and a co-occurring disorder. My interactions with the members of the support group inspired my interest in pursuing this topic for doctoral research.

Much of the existing research on HIV and aging focused on the lives of Anglo Americans. Current literature that addressed living with HIV and the diseases of old age said very little about how these issues manifested in the communities and culture of older African Americans (Psaros et al., 2015; Brown & Sankar, 1998). This researcher's experience interacting with mature HIV+ African Americans revealed a striking counterpoint to the experiences found in the literature describing the lives of mainstream Americans in a similar position.

This current study intends to understand how HIV+ older adult African Americans make meaning of their experience of living with HIV, its strict medication adherence and treatment guidelines, years of balancing visits to different healthcare providers (for treatment of HIV/AIDS and other age-related illnesses) and fluctuating symptomatology—in addition to accommodating to a life of poverty, secrecy, lack of social support, co-morbidity and the stress of aging (Herring, 2006). For many in this population who were still making the adjustment to living with HIV as middle-aged adults, the meaning of having a debilitating co-occurring disorder and the attendant consequences needed to be processed. Finally, by conducting this study this researcher aims to better inform current knowledge on this issue among mental health providers.



**Significance of the Study**

Bassey (2003) asserts that African Americans fall below their Caucasian and Asian counterparts in health and wellness. This fact is especially troubling with the existence of AIDS in epidemic proportions in the African American community. The two groups that constitute the highest rates of new infections in the United States, are African Americans and older adults (Bassey, 2003). The author states that well over 300,000 Americans of African descent are HIV positive. Cases of new infections occur at higher rates among older adults (50+) than among adults under 40. Hence, a more concerted effort appears necessary to effectively reach this population. As the fastest growing segment of the U.S. population is aging Baby Boomers (i.e., people born between 1946–1964), learning about and responding to their physical and mental health concerns, as infection rates rise, become critical (Schutzer & Graves, 2004).

As there is no cure for HIV, and the population of infected middle aged adults and senior citizens will increase significantly over the next 20 years (CDC, 2008), mental health practices that can assess and address the needs of this population may reduce suffering and mortality rates. Without improved knowledge and interventions, older adult HIV+ African Americans will continue to be the HIV population whose future is most dire (Longmire-Avital et al., 2012).

## **Chapter II: Review of the Literature**

### **Introduction**

The following provides a summary of the literature on HIV and aging, as well as chronic diseases with older adults, with mention of the effects of these diseases and aging on African American adults. This chapter is separated into five distinct components: (a) Disease Etiology and progression among the aging, (b) Psychological effects of Aging with HIV, (c) Stigma, HIV and Aging, (d) HIV coping and sociological perspectives, and (e) Coping Strategies for African Americans. Disease Etiology and progression among the aging looks at the effects of HIV and chronic illnesses on older adults. This is an emerging area of inquiry in HIV research. This is followed by an examination of the psychological effects of aging, including issues of cognitive decline, dementia, and depression. Next, this researcher looked at the relevant literature that addressed issues of stigma about HIV for older adults; noting the limitations of the literature in addressing these concerns as they manifest with minorities. Then, seeing that stigma is a constant presence in the lives of HIV+ adults, this researcher looked at styles of coping. Looking at the literature on coping styles of various populations, this researcher hoped to provide some context before finally continuing to move to an analysis of the literature on the coping strategies for HIV+ African Americans, their unique circumstances, and their approaches.

### **Disease Etiology and Progression among the Aging**

Sankar, Nevedal, Neufeld, Berry, and Luborsky's (2011) review of social and behavioral literature regarding the lives of older adults with HIV is a meta-analysis of the existing literature. The authors carefully pored over existing literature about HIV and

aging perusing articles found in the First Search, Proquest, Psych Info, Pub Med, Wilson Select Plasm, and World Cat databases (Sankar et al, 2011). The results suggest the use of gerontological concepts in advancing research among older adults with HIV/AIDS. Characteristics were observed within subgroups. Researchers separated out the groups by transmission mode: Men having sex with Men, Intravenous drug users, and others. The authors noted that because of ageist attitudes and misconceptions about adult sexuality among medical professionals, fewer suggestions for HIV testing were made for older adults. Articles that examined the sexual activity of older adults, highlighted the increased risk of infection pervasive within a society that was reluctant to acknowledge the sexualized experiences of older adults. Additionally, the issue of medication adherence as it intersected with HIV-related dementia and age-related dementia were approached. As adults live longer, chronic diseases as well as HIV become more critical matters.

Investigating the long-term health effects of HIV, Kalayjian and Al-Harthi (2009) suggest that becoming infected at an older age accelerates disease progression and increases the likelihood of a shorter life span. This seems to be true in industrialized nations with access to anti-retroviral therapy (ART), as well as those societies with limited resources (Kalayjian & Al-Harthi, 2009). This may be in part because of delayed diagnosis. One contributing factor is that physicians are less likely to recommend HIV tests for older adults, hence the disease is left to incubate longer and progress (Shippy & Karpiak, 2005). By the time an older person has been diagnosed, their disease has progressed to AIDS. Older adults tend to succumb to HIV more quickly than their younger cohorts because of delayed diagnosis (Inungu, Mokotoff, & Kent, 2001).

Likewise, Kalayjian and Al-Harthi (2009) point out that there are higher incidences of co-morbidities in the older infected groups. HIV associated with kidney disease increases in risk with older age. Rates of dementia appear in higher rates among older HIV + adults. HIV disease is believed to accelerate the aging of the immune system. In an older adult already subject to an aging immune system, infection can be especially deleterious (Kalayjian & Al-Harthi, 2009).

Dyer and Ostwald (2011) explain that our bodies become more vulnerable and functioning impairs as we age. The skin thins and becomes more vulnerable to cancer, heart tissue may calcify, and lungs can become fibrotic, the nervous system can become impaired paving the way for stroke, cognitive impairment, depression, and dementia. Even the appearance of wax build-up in the ears can lead to balance and hearing difficulties as one ages (Dyer & Ostwald, 2011).

With the introduction of highly active anti-retroviral therapy (HAART) in the 1990s, HIV was transformed from a fatal to a chronic disease (Hutton, Santora, & Weiss, 2007). As patients were living longer, researchers began to notice that infected persons were living with multiple morbidities. The triple diagnosis of HIV, addiction, and a psychiatric disorder, expanded to multiple morbidities as the patients aged. The diseases common to older age, coupled with HIV, began to create significant barriers to patient wellness. Scientists possess very little knowledge regarding the long-term health outcomes of persons with multiple morbidities (Hutton et al., 2007). Drug interactions have not been well documented. With high addiction risks in some infected individuals, they are more likely to develop addiction-related diseases including stroke, heart disease, and cancer (Hutton et al., 2007).

Research suggests HIV patients are significantly at higher risk for myocardial infarction (i.e. heart attack) than the general population (Quiros-Rodan et al., 2005). Data from various studies have attributed increases in diabetes mellitus, high cholesterol, and lipodystrophy to HIV antiretroviral therapy (Carr, Samaras, Chisholm, & Cooper, 1998; Vance, Mugavero, Willig, Raper, & Saag, 2011). Although there are some disagreements between studies, data suggests that the medication used to combat HIV is a contributing factor to the rise in diseases that affect older adults, including heart disease (Aberg, 2009; Vance et al., 2011).

Partially in response to data that suggested that antiretroviral therapy contributed to heart disease, Quiros-Rodan et al. (2005) examined the clinical characteristics of 12 HIV positive patients who suffered from myocardial infarction (MI) and compared them to a control group of non-infected participants who suffered from MI. Risk factors such as age, lifestyle, gender, and body mass index were compared between the two groups. Besides the MI risks due to certain lifestyles (smoking, drinking), researchers noted that other variables such as the progression of the virus in the body, and/or opportunistic infections from HIV appeared to be larger contributors to heart attack risks than antiretroviral therapy (Quiros-Rodan et al., 2005).

As individuals age, the likelihood of experiencing certain kinds of dementia dramatically increases. HIV dementia places a long-term survivor at the greatest risk, because it impairs his or her capacity to strictly follow medication adherence (Hutton et al, 2007). There are higher rates of depression that accompany dementia and various physical and cognitive disorders. As the understanding of these phenomena of multiple morbidities is recent to medical science, it is also just beginning to be explored in mental

health (Kalayjian & Al-Harthi, 2009). The physical affects notwithstanding, the psychological effects of living with HIV, HIV-related dementia, and other comorbidities are an emerging byproduct of individuals living longer, and are just beginning to be examined.

**Summary.** A meta-analysis of HIV among older populations suggests, in part, that disease etiology within this group manifests because of delayed diagnosis. Simultaneously, as adults live longer resistance to age-related diseases becomes challenging. HIV exacerbates their incapacity to recover from illness, inhibits cognitive functioning, and increases physical decline. So even with the introduction of HAART therapy, older adults continue to face significant health issues. This paper will examine what this may mean for African Americans specifically, who may struggle with these issues.

### **Psychological effects of Aging with HIV**

Looking at cognitive decline in adults aging with HIV, Vance, Ross, Moneyham, Farr, and Fordham (2010) analyzed and discussed suicidal ideation in older infected individuals. They reported that successful aging is contingent on maintaining stable cognitive functioning. In normal aging some cognitive decline is not uncommon. The executive function capability of the prefrontal cortex, the area responsible for analyzing and solving problems, experiences some reduction (Vance et al., 2010). Researchers observe that as people age their cognitive reserves (the ability of the brain to physiologically rebound from insults and continue to function) decline (Vance, 2013).

HIV+ older adults are saddled with possible cognitive decline from aging, which may be exacerbated with the increased risks of cognitive impairment from AIDS related

dementia (Vance et al., 2010). The symptoms of HIV-related cognitive decline can be correlated with social stigma, depression, social withdrawal, lowered self-esteem, and other negative emotions (Vance, 2013). This “double jeopardy,” as the authors refer to it, can lead to cognitive impairments from normal life stressors. Vance et al. (2010) suggest that this “cognitive decline may actually cause perseveration in the brain; the fixated, inordinately focused thoughts that tend to be negative by nature” (p 153). This can lead to depression and suicidal ideation.

More so than uninfected seniors and infected youths, HIV+ older adults have increased incidences of depression and suicide ideation (Carrico, 2010; Vance et al., 2010). The heightened sensitivity and vulnerability of this population can make them fragile to social disapproval. Even after the introduction of ARVs the suicide rate among HIV+ adults is three times higher than that of the general population (Carrico, 2010). Researchers assert that there may be a biological component to elevated suicide risks among HIV+ persons (Carrico, 2010). They commented that the virus alters the body’s immune system and upsets the biochemical activity of the brain, specifically affecting serotonin levels. Research indicates that depression is a biological result of the HIV’s effect on serotonin (Carrico, 2010).

**Summary.** HIV has been shown to be deleterious to emotional as well as cognitive stability, upon which healthy aging is contingent. Depression and suicide ideation for infected older adults is higher than the rest of the older population. Given these challenges for older adults, this study is interested in understanding how older African Americans make sense of their condition who may also be struggling with these

issues. This is very important as this paper shifts focus to problems with stigma that persists around HIV.

### **Stigma, HIV and Aging**

Although HIV stigma is on the decline in general in American society, people are still uncomfortable around infected persons (Emlet, 2006). In a qualitative study that looked at stigma toward the aged living with HIV, Emlet (2006) wanted to see how it manifested in their lives. Twenty-five interviewees participated in the qualitative study in which they revealed in-depth accounts of their lives of interacting with society as HIV+ positive older adults. Seventeen men and eight women took part in individual 1-2 hour interviews, and were paid \$25. Many gave personalized accounts of rejection because of infection and/or old age.

From the series of interviews nine themes emerged: *rejection, stereotyping, fear of contagion, violations of confidentiality, internalized ageism, social discrimination, institutional discrimination, anticipatory stigma, and other* (Emlet, 2006). The gay participants spoke of being treated poorly by their younger gay male peers. This rejection was intensified once it was discovered that the older gay adult was infected. Especially noteworthy were fears among the non-gay infected adults of the stigma of being associated with infection through gay sex.

Also, participants mentioned how caretakers and healthcare workers violated their patients' confidentiality and divulged the HIV status to the families without consent. Interviewees shared accounts of healthcare workers neglecting them, or family members' reluctance to touch them. Emlet (2006) revealed the heretofore unstudied phenomena of



ageism and stigma among HIV infected older adults. But despite the ageism and stigma, and the inevitable depression and suicidal ideation, some managed to persevere.

Storholm et al. (2013) assert that various studies on HIV-related stigma have focused on the effect of stigma on a group (e.g., gay, IV drug users), but have failed to consider that the experience of stigma may not be the same for all persons. Lacking are studies that target individuals with more than one marginalized identity (e.g., older African American lesbian) and mental health challenges that result from the HIV-related stigma. Positing the Minority Stress Theory, which asserts that persons with non-mainstream identities may be at higher risks for mental health problems, Storholm et al. (2013) suggest that multiple minorities experience unequal treatment across many domains which include housing, healthcare, education, employment, and political systems. This accumulation of unequal treatment, for the multiple minorities, contributes to their mental health issues. Storholm et al. (2013) argues the Minority Stress Theory helps explain the hiding, isolation, the feelings of rejection, the expectation of intolerance, and poor coping skills of older HIV positive African Americans.

In 2013, Hansen, Harrison, Fambro, Heckman and Sikkema published a study that looked at the coping strategies of older adults living with HIV who experienced “double stigma” (Emlet, 2006) because of their advanced age and HIV status. Among the first studies of its kind, the researchers set out to test their hypothesis that long-term survivors with depression had developed specific coping skills to adjust to their diagnosis and aging.

Two hundred five men and 102 women, with an average age of 55, participated in the study. Most had been living with HIV for 13+ years. The sample was ethnically

diverse with just under 50% who were African American, and just under 50% gay identified. Interviewees were given a 61-item questionnaire that was culled from various assessment instruments that measured coping strategies (e.g., Coping with Illness Inventory). The result was the development of a coping model that consisted of five domains: *active coping*, *social support seeking*, *spiritual coping*, *avoidant coping*, and *self-destructive coping*. Participants' scores were compared against pre-existing psychometric tools for validity (e.g. Beck Anxiety Inventory).

The results of the study appeared to correlate with the hypothesis that participants who used social support, active coping, and spiritual coping generally had declines in depression, loneliness, and increases in self-efficacy (Hansen et al., 2013). Conversely, individuals who used avoidant coping and self-destructive coping had increases in depression, loneliness, and decreases in self-efficacy. While the study was limited in scope, it helped illustrate some possible guidelines for treatment of older infected adults. This study was quantitative in nature and useful in providing context in how older adults created coping skills. The current study seeks to probe deeper through qualitative study to understand how older adults make meaning of living with HIV and a comorbid condition.

**Summary.** Stigma remains a powerful negative emotion in the lives of infected persons. Stigma, real or imagined, has caused many people to withdraw from friends, family, and society. Older adults are more acutely affected by stigma as they are a more vulnerable population. Rejection from younger gay males, lack of sensitivity from healthcare providers, and misinformation among family and community can make coping a challenge for older adults. This literature also provided a quantitative study to contextualize how mainstream Americans, as well as African Americans have developed

strategies for living with HIV-related stigma as they age. However, the intent of the proposed study is to qualitatively consider other possible responses to stigma looking specifically at African Americans' experiences in varying contexts, as well as to broaden our scope to include an understanding of the lived experiences of older HIV+ African Americans having to adjust to the added stressors of age-related illnesses.

### **HIV Coping and Sociological perspectives**

Shippy and Karpiak (2005) suggested that as people with HIV age into their later years, social support becomes a salient resource for coping. To test their hypothesis, 160 participants from New York City were recruited into a study. Eighty-nine percent of the participants were people of color. Researchers looked at their lives, social interactions, and current epidemiological data. In addition to the strain of living with HIV over a longer period, researchers noted older adults must confront social stigma, ignorance, and discrimination resulting from HIV/AIDS. As public perception persists that HIV remains a health issue of the young, AIDS service organizations are remiss in not tailoring education and advocacy toward older adults (Shippy & Karpiak, 2005). Equally troubling is the social isolation that older adults face from younger HIV-positive people. Study participants confessed that they were reluctant to divulge their HIV status to friends and family for fear of stigmatization and abandonment, thus confining themselves to lives lacking in social support. Depression is a common factor with this cohort as feelings of isolation and withdrawal contribute to the older adult's unrealized social and emotional needs. HIV and age-related morbidity are allowed to flourish in the older adult's life when their capacity to cope is compromised by a fragile social network (Shippy & Karpiak, 2005).

In the face of the physical and cognitive decline of aging and infection with HIV, studies have shed some light on how the infected are coping. Emlet, Tozay, and Raveis (2010) addressed resilience among the population of middle-aged seropositive people. The Center for Disease Control has documented a steady rise in HIV infection in adults over 50 years old since 2006. This included the long-term survivors as well as the recently diagnosed. Emlet et al. (2010) initially focused on the negative effects felt by long-term survivors, such as loneliness, shame, stigma, discrimination, depression and suicidal ideation. These negative effects were keenly felt, according to their study. The original intent that the authors proposed for their study was to continue along that same vein and explore the feelings of shame and stigma felt in HIV older adults. What emerged, serendipitously, was a portrait of resilience and personal strength in this population.

Emlet et al. (2010) used a positivist approach, that is described a phenomenon that is observed and measured, in the collection and collation of their data. Twenty-five adults aged 50–72 were interviewed in a semi-structured fashion. Participants included were African American and Anglo American, as well as male and female. HIV transmission with the participant group included male/male sex, male/female sex, IV drug use, and other. The transcripts for the interviews were read, coded, and analyzed for various themes. From the themes that frequently emerged from the study, researchers developed a conceptual framework. The overarching themes that were synthesized from the transcripts were resilience and strengths perspective. From these constructs seven major themes were culled. They included self-acceptance, optimism, will-to-live, generativity, self-management, relational living, and independence (Emlet et al., 2010).

Rosenfeld, Bartlam, and Smith (2012) examined aging with HIV for gay men from the “life course perspective.” The authors defined life course theory by explaining how human lives are shaped not only by such features as class, sex, and ethnicity, but also by birth year and cohort status, which represents the distinctive exposure of those born at a certain time of social change. Collective properties are assembled from historical events and contexts on persons of a similar age; the macro-social forces that resonate on micro-social personal levels. For example, the Great Depression changed the way many people spent their money, lived and voted. Similarly, the protest movement of the 1960s and 1970s affected the political, environmental, and social concerns of many citizens. Within the cohort of Baby Boomers, those people typically understood to have been born between the late 1940s to the mid 1960s, there is a sub-cohort of gay men who came of age in the late 1970s to the mid 1990s. What is unique of this sub-cohort is that they formed communities in the late 1970s and early 1980s typically in large urban centers, that were gay positive, sexually open, and contained many social networks, which may have been influenced by the beginning of the gay rights movement. Within these diverse urban centers, HIV devastated the communities and irrevocably altered the lives of these men. Over an 11-year period between 1987 and 1998 some 324,097 people died from HIV or AIDS- related complex. With the arrival of AIDS retroviral therapy (ART) deaths declined in this community, but two new sub-cohorts emerged. The first consisted of those men who were infected before ART, who witnessed the deaths; experienced the illness personally, saw more stigma, and economic hardship. The second, post-ART, consisted of those men who at middle age and older age were newly infected and struggling with infection and age-related co-morbidities. In both of these groups the

authors addressed the elements of the life course perspective. The elements include interdependence, agency, and timing. For example, research addressed the gay men's social network but not in the mode of interdependence, that the social networks and the men who created and sustained them were unique and synergistic. Existing research does not cover agency, the way gay men rebuilt their social networks, relations, and identities in the wake of the epidemic (Rosenfeld et al., 2012). Similarly, available research overlooked timing, the convergence of Baby Boomers who are gay and the socio-historical processes of the rise of the open, urbanized queer-positive community; how their experience with HIV occurred at their early adult through middle age to shape them later in life. The timing of the epidemic altered life plans, health expectancy, and employment for this cohort. The combination of these events over the 10-year period shed light on the effects of long term illness in a variety of areas of these people's lives today. The authors noted the lack of research that studied the consequences and management of HIV deaths among same gender loving black men in the African American community.

In Vancouver, Canada, millennial gay men approaching their middle and senior years shared their stories in historical narratives (Wallace, Petty, Patton, and Kang, 2008). Participants detailed accounts of living with HIV through the 1980s, 1990s and into the first decade of the new millennium. Coming from an era where AIDS was primarily thought to be a disease of the young, the long-term survivors spoke of enduring stigma from the gay community for aging out of a youth obsessed culture, and for being infected (Wallace et al., 2008). Ironically they suggest that these long-term survivors developed coping strategies of creating cohorts with other newly infected men that

included support groups and political activism. The authors described how some of the long-term infected men struggled with living financially marginalized lives due to the fact that they were unable to work. By virtue of being in the workforce longer, the newly diagnosed middle aged and older gay men were noted to possess more financial resources than their long-term counterparts; but still had to adapt quickly to the psychological realities of living with a deadly, albeit manageable, disease. Wallace et al. (2008) note in the 2000s that while homophobia may have declined in society, these men now had to acclimate themselves to aging with a disease. Political activism is less engaged with the injustices of society and more engaged with fighting for community-oriented services that was essential for these men.

Longmire-Avital et al. (2012) looked at existing literature and hypothesized that because of lower socioeconomic status, education, and healthcare, older adult HIV-positive African Americans have higher degrees of perceived hardships. The authors recruited 377 HIV-positive African Americans from New York City to participate in a study with the aim of seeing whether they could predict through perceived hardships, a model of life satisfaction for older adult infected African Americans. Measurements included a single life satisfaction scale, single item self-related physical scale, a questionnaire that assesses for perceived strain, and a depression scale. The results revealed that perceived financial strain is an important and significant predictor of life satisfaction. This is especially applicable to a cohort of HIV-positive aging African American people who have little possibility of increasing their financial resources. The measurements of the study independently verified that continual financial struggle exacerbates psychological stress for older infected African Americans. The researchers

noted that even as antiretroviral drug therapy have been able to reduce HIV, older adult African Americans still struggle with multiple-age related chronic illnesses on limited financial resources (Longmire-Avital et al., 2012).

**Summary.** Stigma, ignorance, and age discrimination from an HIV diagnosis can make coping difficult for infected older adults. As people age, social support becomes an important resource for coping. Older adults are often ignored by their younger counterparts. Much of community resources for HIV are focused on younger people.

Despite these problems evidence suggest that some older adults of different races have shown resilience, self-acceptance, and the will to survive. This is especially true for older gay men. Among the most severely afflicted, they have formed social networks, support groups, and lobbied for social services. More problematic is how many older African Americans, as a racial minority, who lack the economic, political, and social capital of their gay counterparts, are able to cope. Quantitative study links lower life satisfaction measures and feelings of hardship measures as more prevalent among infected older African Americans. In light of the literature on coping, this study intends to more fully explore how African Americans cope not only with HIV, but also bear the burden of coping with an age-related, chronic illness.

### **Research on Coping Strategies for African Americans**

The struggles of African Americans to disease in general, and HIV, in particular, has resulted in varying styles of coping. African American gay-identified males, transgender, or men who have sex with men (MSM), experience disproportionately high rates of infection (Philips et al., 2011). For MSM in the United States, African American males are among the highest population of HIV infected persons; with one study



indicating a prevalence rate of 46% for African American MSM compared to 21% in Anglo MSM in five metropolitan areas (CDC, 2013, as cited in Dickson-Gomez et al., 2014). Research suggests that the high infection rates are not attributed to higher drug use, or incidences of unprotected sex, or lack of information about HIV transmission, but because of perceived homophobia and racism—risky behavior fueled by a sense of isolation (Dickson-Gomez et al., 2014). For the African American youth who were rejected by their birth families, churches and community, the House and Ball cultures provided a source of support enabling these young men to cope (Philips et al., 2011; Dickson-Gomez et al, 2014).

The House and Ball culture was one place where working class African American men gathered and socialized. Dating back to Harlem in the 1920s, it continues to exist today in cities and large urban centers throughout the United States. Houses are a constructed family and include older men of color who act as the “mother” or “father” to the children (younger men) who are counseled, taught, mentored, and protected by the “mother” and “father.” The children represent their house as they compete in ball competitions (social events) in drag or masculine attire. These houses provide a safe space for youth to cope with their gay or transgender identity by acting as a support system for the young men who may have been rejected by their birth families or society (Philips et al., 2011; Dickson-Gomez et al, 2014).

Ethnographic research, according to Dickson-Gomez et al. (2014) in their analysis studied the importance of constructed families for African Americans. Constructed families may include relatives (play-aunts, play-uncles) who are not biologically-related, but nonetheless are treated as though they were. Extended family can include neighbors

and friends who look after, and protect the children. This kind of family structure dated back to the 18<sup>th</sup> century slave era. It has been seen as a source of resilience for many people of color. The constructed families of the Houses and Balls have become social and emotional buffers for African American MSM who have been rejected by their churches and families. Constructed families were often places that these youths sought out even if their biological families did not reject them. Having someone who understood you and that you could trust was important. The Gay Men's Health Crisis, in New York City, in an attempt to stem the rising tide of HIV infections among African American males, partnered with Houses in New York City (Dickson-Gomez et al., 2014). For example, the House of Latex was formed to help educate and encourage young MSM to practice safe sex and to spread awareness about sexually transmitted diseases and HIV. Hence, a mechanism to support young MSM also exists to help halt the progression of HIV within their population.

Similarly, support systems have been shown to be efficacious for people of color struggling with health issues. African Americans experience hypertension more acutely than other races (Heard, Whitfield, Edwards, Bruce, & Beech 2011). In their research to examine the connection between well-being and the environmental components that influence hypertension, Heard et al. (2011) hypothesized that hypertension and stress could be moderated by social support and improved health outcomes. In their study two sample groups were assembled and tested. One group, the Carolina African American Twin Study of Aging, included 395 participants, and the other, the Baltimore Study of Black Aging which included 602 participants, were tested for hypertension, asked questions about symptomatology of depression, social support, and perceived stress.

Findings showed that improving social support helped to minimize the negative effects of depression on blood pressure.

Social support very often came from religious institutions, which were for many people of color the center of spiritual, educational, and social life (Stewart & Dancy, 2012). Information about health, both spiritual and physical, disseminated from pastors and laypersons, enabled parishioners to acquire vital knowledge that they were inclined to trust. In their ethnographic study to understand why churches engage in an HIV ministry, Stewart and Dancy (2012) interviewed and observed a large urban church with a longstanding HIV ministry. Pastors, including the senior, associate, and the pastor emeritus, along with parishioners were interviewed about the ministry, their spiritual beliefs that informed their ministry, and what they were doing to perpetuate the ministry.

The synthesized data from their research indicated a shared fundamental belief that HIV ministry was important to support because the work was an example of acting in accordance with Christ's commandments, and it enabled African Americans through ministry to advocate for other African Americans. Stewart and Dancy (2012) noted in their analysis of previous studies about faith and HIV, that a link existed between parishioners who accessed HIV care when exposed to HIV ministries. The support of churches encouraged healthier behavior in their members.

In matters of mental illness, research indicates that community support is lacking due to stigma and cultural misconceptions; thereby inhibiting African Americans from seeking clinical care to address mental health concerns (Ward, Wiltshire, & Brown, 2013). People of color seek treatment for mental health concerns at a rate of half of their Anglo counterparts (Brown & Palenchar, 2004). In their study focused on understanding

African Americans' beliefs, attitudes, about mental illness, and ways of coping, Ward et al. (2013) observed that depression was the most common disorder among people of color, irrespective of age or gender. The study data revealed that African Americans culturally prefer to cope with their distress by appealing to their faith.

A popular notion researchers observed among this population, is that in collaboration with God a person could endure the vicissitudes of life (Holt, Clark, Debnam, & Roth, 2014). With this positive religious coping, there was a correlation between better emotional states and even healthier eating habits.

This was especially true for older African Americans (Marks et al., 2005). In a study that examined the link between religion-health-longevity, they conducted semi-structured interviews of 32 middle-aged African Americans. Using grounded theory to analyze their data six themes emerged. The participants believed: (1) active faith involvement contributed to a healthy life, (2) leaning on strong faith resources helped avoid negative coping, (3) evading violence and appealing to church structure shielded them from street life, (4) avoiding the absence of hope and not giving up on faith kept signaled that they were not giving up on life, (5) seeing other church members as extended family, and (6) using prayer to overcome feelings of hopelessness and helplessness. Stress and worry can be given over to God.

Cultural methods of coping are important to understand in light of research indicating older African Americans suffering from depression were resistant to seeking treatment (Brown & Palenchar, 2004). Often seeking treatment at half the rate of Anglo counterparts, the practice of relying on faith as a coping mechanism for mental illness stems in part from exposure to racism, discrimination, and poverty (Brown, 2003;

USDHHS, 2001). Conceptualization of mental illness, specifically depression, reveal cultural barriers that also contribute to the reluctance of older African Americans to seek treatment. For example, studies revealed that some believe that depression naturally occurs because of old age, that treatments involved taking pills that can become addictive, and that symptoms and the suffering is something that should be kept to one's self and not made public (Connor, et al., 2010, Connor, et al., 2010). Depression exists and is more acutely experienced by older African Americans because of entrenched social injustices attributed to societal racism and triggered by the experience of personal loss (e.g. disease, divorce, death; Black, Gitlin, & Burke, 2011). As treatment for mental illness and general health concerns lag for older African Americans, more research needs to be done to address ways to minimize this disparity.

**Summary.** HIV in the African American community has resulted in people developing various ways of coping. MSM, who were rejected by their churches and families, formed houses where they created surrogate families that promoted and protected the young men. Houses became the venue where these men not only received validation; they were also important social and health-related support systems.

Whereas, older African Americans learned to cope with chronic disease in general by relying on social support (e.g., church family) and faith. But when confronting HIV and mental illness which can be acutely experienced by older African Americans, they relied on familiar cultural traditions of turning to faith, but also denial, misconceptions, and misinformation. Often this could lead to a person feeling more spiritually-grounded, but also could leave them with poor health outcomes and depression.

Current literature provides some context on aging with HIV and the social, physical, and psychological ramifications. Some of the limitations of the above-referenced studies were that they were quantitatively based (e.g. Baltimore Black Study of Aging, year; Longmire-Avital study, 2012) measuring the infected populations' experiences globally. For example, coping as described above is measured in a psychometric instrument and is limited in its explanation for ways of coping. However, it can be argued that using qualitative inquiry one may be more able to freely investigate the different ways in which a person may cope (Pestana, 2015). In addition, much of the research that addresses aging and HIV speaks to the experience of the mainstream population, but says little about the lived experiences of African Americans. While there may be some overlap to this study's inquiry within existing literature, insufficient data has been culled that addresses the unique combination of diverse co-morbid conditions and their attendant effects on the body and psyche of Black middle-aged and older adults infected with HIV. The purpose of this study is to examine specifically the lived experiences of age-related co-morbidities and HIV on this population and aims to fill this gap.

### **Chapter III: Method**

This study uses Interpretative Phenomenological Analysis (IPA), a qualitative method of inquiry for clinically based research. It is a tool of applied psychology, a study of what happens in the “real world.” (Smith, Flowers, & Larkin, 2013). IPA’s path is dedicated to understanding how persons make sense of their important life experiences. Using the data acquired in semi-structured interviews, this researcher employed IPA to understand the lived experiences of older adult African Americans living with HIV and a comorbid condition. One of the main methods of analysis in IPA is for a researcher to locate concurrent themes from participant interviews. (Smith et al. 2013). IPA as a research method captures the experiential and qualitative, yet still retains the capacity to talk with mainstream psychology whose focus is primarily quantitative (Smith et al., 2013). IPA encourages an interviewer to look at how language and culture are frameworks for understanding the psychological reality of an interviewee (Smith, Flowers, & Larkin, 2013). The interviewer uses this framework to help understand how a participant makes sense of their experience.

#### **Characteristics and Rationale for Method**

Interpretative Phenomenological Analysis as a qualitative method uses interviews in order to obtain rich, in-depth data. Interviews tend to be less structured, and questions more open-ended (e.g., semi-structured). Within a research setting that is less structured, participants are free to share their stories, and clarify some of their experiences. Smith et al (2013) assert that IPA consists of three philosophical pillars: Phenomenology, Hermeneutics, and Idiography. Phenomenology is concerned with what the experience of

being human is like. To gain a better understanding of the experiences of being human, phenomenology attempts to enter into the “life world” of a participant (Larkin, Watts, & Clifton, 2006). Hermeneutics, the second philosophical pillar, is interested in how something is interpreted, the thought(s) that inform the choices that are made in making interpretations. Smith, et al. (2013) also discuss the inevitable reality of “double Hermeneutics”: wherein the researcher attempts to make sense of how the participant makes sense of a particular thing or event. Drawing from the writings of Heidegger, Smith et al. (2013) highlight that a researcher inserts herself into the discourse by drawing upon her own history, knowledge and experience to make sense of what is being interpreted, while remaining faithful to presenting participant’s experience. Idiography, the third philosophical pillar, is focused on the particular: the specific details of a thing. An idiographic approach is the opposite from a nomothetic approach; rather than count from larger samples and make deductions about an element of human experience, idiographic inquiry is inductive and looks at the details of particular phenomena in a small sample and observes the similarities, with the goal of possibly understanding something more substantial about the human experience (Smith et al., 2013). IPA researchers select participants because of a phenomenon or process that they are undergoing.

Interpretative phenomenological analysis is a well-used tool of qualitative-based research in clinical, health and social psychology, that addresses issues such as HIV, sex, sexuality, illness, identity, and psychological distress (Smith et al., 2013; Brocki & Wearden, 2006). As a qualitative method for better understanding the experiences of persons living with HIV/AIDS, IPA has enabled researchers to move beyond biomedical



indicators to explain health phenomenon (Vella, 2015). Much of HIV/AIDS research has focused on biomedical clinical markers of health to conceptualize health related experiences for people living with HIV/AIDS (Wong & Ussher, 2008).

This study aimed to have persons living with HIV/AIDS share their stories, perceptions, feelings, and experiences; specifically, to give voice to the older adults within the African American community living with HIV and the diseases encountered in aging. Through semi-structured interviews African American cultural perspectives on these issues were examined. The psychological experiences, including cognitions and affect, the specific details, and the particulars of the phenomena were gleaned. This approach was chosen because it enabled this researcher to learn about a group of different participants' lived experiences and see how they may be similar to each other. The researcher's personal involvement with HIV+ older African American adults has included work with those who are affected and infected. As a facilitator, this researcher's knowledge and experience supplemented his making meaning of how the participants make meaning of their experience of the phenomena (Smith et al, 2013). Additionally, Smith and Osborn (2009) assert that utilizing semi-structured interviews facilitates rapport building, produces empathy, and permits the researcher to flexibly investigate different themes with the participants (Smith & Osborn, 2009, as quoted in Pestana, 2014). The need to acquire detailed personal narratives and the need to deeply explore how the African American participants make sense of their experiences, may best be fulfilled by IPA.

## **Research Questions**

Some questions to clarify the inquiry may include: Can we describe the range of emotions, good or bad, that the client experiences? Are the emotions and coping strategies different for HIV compared to co-morbid conditions? What are their coping mechanisms? What are the differences in coping styles, if any, between men and women? Can we identify any mitigating influences (faith, family, friends) that the client has to draw on to help navigate the conditions? What culturally competent therapeutic practices target these problems for this population?

## **Data collection and Analysis Overview**

Qualitative data collection usually involves interviewing persons directly familiar with the phenomena. Any information that assisted the researcher in ascertaining and understanding the range of affect experienced by the participants' reaction to the phenomena was incorporated in the analysis. The transcripts were read and re-read and analyzed for any non-verbal para-linguistic communications (e.g., facial expressions, body language) for the general meaning. Giving careful consideration to be cautious of researcher bias and projection, the interviewer analyzed the interview recordings and transcripts to get the general meaning by attempting to understand the world of the participant-interviewee (Hycner, 1985). The general meaning was pared down by eliminating irrelevant data and redundancies and then clustered into groups of broad themes. The broad or general themes will be pared down to specific themes using IPA. This included noting non-verbal communication. The analysis of the data evolved from significant statements to a more nuanced understanding and answering of the questions such as what did they see and how did they feel (Creswell, 2013). The data was coded,

labeled, and analyzed for themes using IPA. The interviewer read the transcripts of each of the interviewees and looked for themes that came up in the participant's description of their experience and how they make meaning from it. Those themes were coded, and compared to similar or different themes that are found among the various interviewees. The multiple similar themes that appear across transcripts were labeled, and from an analysis of those themes superordinate themes were created. The description of the phenomena as experienced by the participants was distilled in this kind of qualitative study (Creswell, 2013). It is this richer awareness that has provided study results that enabled this researcher to hone in on clients' experiences. This process using IPA will be discussed in greater detail in this chapter.

### **Participant Sampling and Inclusion Criteria**

The study explored the lived experiences of older African American people who have HIV/AIDS **and** an age-related comorbid illness. In order to acquire as much information-rich data as possible, this study recruited participants through purposeful sampling. Purposeful sampling encourages that participants be deliberately chosen because of the particular characteristics of their population, and their ability to provide unique data about themselves and their experiences, enabling the researcher to answer the research question. In addition, purposeful sampling aided in acquiring diversity in the voices. The researcher's sampling strategy was to look for different sexual and gender identities, ages, and levels of education. The qualitative sampling technique that this researcher used was criterion-based sampling.

Criterion-based sampling is commonly used in phenomenological studies. This sampling technique specifically seeks out volunteers to be studied who have experienced

the same phenomena (Bloomberg & Volpe, 2012). Smith et al. (2013) outlined in IPA methodology that a sample set be purposefully selected based upon specific inclusion criteria. For the purposes of this study the criteria for participation inclusion required that participants identified as African American or Black, be of any gender presentation, at least 50 years old, HIV-positive, and currently living with at least one age-related illness (e.g., heart disease, diabetes, cancer, high blood pressure, dementia) or co-morbidity.

IPA as a method of qualitative research does not specify a correct sample size (Smith et al., 2013). Studies that have used IPA have ranged from a single case study to studies that have involved several dozen in the sample set. However, participants are of interest not because they represent a population, but that they have a perspective, as in this study—a unique perspective (Smith et al., 2013). In choosing a sample size richness of a case and level of analysis dictate the quality of a study more than size (Smith & Osborn, 2008). With larger sizes in IPA the researcher reveals how primary themes appear and reappear with a group (Smith et al., 2013). The specific details from individual participant experiences are offered as evidence for nuances of reappearing themes (Vella, 2015; Smith et al., 2013). To present as diverse a range of experiences to satisfy doctoral-level work, but keep the study of sufficient size to answer the research question(s) and stay true to the voices of the participants, and work within given time constraints, a sampling of ten (10) was chosen.

## **Recruitment**

The sample was selected from among individuals who access services at community health clinics/agencies that serve the HIV population in a large urban metropolitan area. Because of the sensitive and secretive nature surrounding the illness

for the population this researcher interviewed, a gatekeeper had been identified to aid in disseminating recruitment materials (Appendix D) to potential volunteers, and to assist in introducing the researcher to other HIV agency representatives and healthcare providers (Smith et al., 2013). The gatekeeper is the director of an HIV community health agency who assisted the researcher by helping facilitate contact with the heads of other area HIV agencies, and/or contact with persons who utilize the clinics' services. By arranging the introduction with contacts at other HIV service agencies, the gatekeeper enabled this researcher to have access to a pool of several dozen possible candidates of whom this study selected 10 participants.

Participants recruited from local HIV-related health clinics/hospitals responded in three ways: to flyers that were distributed, to recommendations from other HIV service providers, and to suggestions given to them from other clients. Snowballing technique, which included enlisting the recommendations of other possible participants from interviewees, enabled this researcher to enlist a diverse sample. As all of the participants were clients of local HIV service providers, no personal medical records were requested to verify serostatus (e.g., status for being positive or negative for HIV). However, the researcher relied on self-report for information about a participant's co-morbid condition(s).

This study primarily sought African American persons who have HIV and are aged 50 or older. The researcher actively recruited both male and female African American volunteers from ethnically, socially, and religiously diverse backgrounds for the sake of heterogeneity within this subgroup, and with the intent to reduce possible bias. During initial screenings potential participants were briefly queried about age-

related disease(s) they had. Because the researcher was living outside of the state during the recruitment, recommendations of potential volunteers identified by staff at participating HIV-clinics, and initial contact with interested candidates was done over the phone. Participants were called, screened and appointments for the interviews were scheduled over a three-month period. Once a minimum of 10 participants had been recruited, these volunteers were informed about the content and purpose of the study.

### **Procedures**

This paper is intended to present the lived experiences of a particular subset of the population of persons living with HIV. The results of this study will hopefully add perspective to existing knowledge, and provide insight for mental health providers. As such, participants are thought of as co-creators of the knowledge that will inform clinical practice with this population (Cornwall & Jewkes, 1995). Taking a participatory research approach in collaborating with interviewees, the researcher hereafter refers to the study participants as informants.

With the initial face-to-face contact with informants, the researcher made casual conversation to help make them comfortable and orient them to the interview format. Informants were asked to read, accept, and sign a consent form. The consent form consisted of information about confidentiality, any limits to confidentiality, a request to do a semi-structured interview, and a request for consent to audio record the interview. Because informants had not received the consent form prior to the semi-structured interview, they were encouraged to read it first, make inquiries, and give their assent by signing the consent form before the interview commenced (see Appendix A).

Next, informants were asked to complete a brief demographic questionnaire (see Appendix B). The demographic questionnaire requested that informants provide answers regarding the race to which they identified (e.g., African American, Black, Haitian), the gender they identified with, their age, highest level of education attained, sexual orientation they identified with, and which age-related diseases do they have.

An in-depth semi-structured interview was the main tool for data collection in this study. Smith et al. (2013) characterized it as a “conversation with purpose” (p. 57). The nature of a semi-structured interview allows the researcher and the volunteer to be co-participants in the process (Smith et al., 2013). In order to encourage the informants’ comfort, ensure confidentiality, minimize to the greatest extent possible any appearance of coercion, and to create an environment that facilitates acquiring data-rich information, the researcher allowed the informants to select the site for the interview (Smith et al., 2013). Only one informant chose to conduct the interview in a location other than the HIV community clinic. That interview was conducted in the informant’s home. The other interviews were conducted in a secure and private location in a community health clinic. All of the interviews were conducted by James Chavers, Jr.

The schedule of questions that were generated for the semi-structured interview derived from interaction with HIV-positive older African American members of a support group that the researcher facilitated, and from literature that addressed the issues confronted by older African Americans living with HIV. The interview questions (Appendix C) were open-ended and expansive and designed to encourage a comfortable interaction (Smith et al., 2013). The interview questions were divided into three sections. The first three questions were straightforward and designed to elicit descriptive answers

(e.g., day-to-day experiences, feelings and thoughts) as well as help acclimate interviewees into talking about themselves (Smith et al., 2013). The middle group of questions were connected to informants' internal and external coping resources (Earnshaw, Bogart, Dovidio, & Williams, 2015). The last three questions were more abstract and asked informants to interpret certain experiences (e.g., what is HIV to you, how have feelings changed). The researcher attempted to design the schedule to enable the informants to tell the interviewer what it is like to exist in their personal world (Smith et al., 2013).

In the beginning of the interview session each informant was explicitly told that there were no right or wrong answers to the questions, only your truth. The researcher was careful to give prompts when the informant provided brief or unclear answers. The most often used prompt was "Can you tell me more." This prompt was used to encourage the informant to go deeper (Smith et al., 2013). The interviewer used silence as a cue to enable an informant to expand on an answer or pick-up on a topic and give more detail (Smith et al., 2013). Informants responded to questions in a variety of thought-provoking and interesting ways. Not all questions or prompts resonated with every informant. For example, only one person directly answered a question about the experience of having HIV as an African American. While the interviewer expected some of the informants to be loquacious, one of them despite prompts, encouragement, and silence, was brief and terse with answers. This interview at the informant's request was conducted at the informant's home, and the person appeared relaxed, open, friendly, and not nervous. The interviewer completed the interview, circled back, and re-asked the informant the same questions using different language with slightly better results. The researcher attempted



to structure the pace and rhythm of the interview to the informants' comfort. Some of the informant responses to questions veered off topic and were tangential. The interviewer did not interrupt the informant, but attempted to gently steer (e.g., re-ask the question) the interview back to the topic. When an informant became tearful, the researcher paused the interview and checked in with the informant. It was only with the informant's assent that the interview continued. All of the informants appeared pleased with the prospect that their stories would be told. Some mentioned that they were interested in learning about the study findings.

Each interview lasted approximately 30–90 minutes and were recorded with an Olympus VN-7200 digital voice recorder. The interviewer wrote field notes during each interview session that attempted to capture non-verbal and verbal cues from the informants, as well as personal impressions of the informant and session. All of the transcription was done by the interviewer. Any names, titles, and/or identifying information for the informants were changed to keep their identities anonymous during transcription. The researcher ensured confidentiality by using a code for each of the informants' names. Each of the informants were later given a pseudonym. Every effort has been made to maintain strict confidentiality of the participants' identities. As volunteers signed consent forms, the recorded data, notes, interview tapes, and consent forms are coded with numbers for the names of the interviewees, and locked away in a secure location, with the information accessible only to the researcher and the members of the dissertation committee. The numbers that match the names will be kept in a separate secure locked location. Only the researcher and the dissertation advisory committee have access to the data. The IRB committee reviewed the above referenced

procedures to ensure compliance to rules of confidentiality. The researcher carefully reviewed the confidentiality procedures with the volunteers before asking for participants' signature on the consent forms.

### **Data Analysis**

Although IPA does not prescribe a single definitive account for how to analyze data, because the researcher is a novice of IPA, the methods outlined in Smith et al. (2013) were closely followed. All of the audio recordings of the interview, transcript data, and field notes was analyzed by the researcher following the IPA analytic process. The following is a description of the IPA analytic process and a step-by-step description of how the researcher analyzed the data.

Smith et al. (2013) outlined the following six steps for IPA coding analytic process: reading and re-reading; initial noting; creating emergent themes; locating superordinate themes in each case; moving to the next case; and developing superordinate themes across cases.

**Reading and re-reading.** Step one of the analytic process included reading and re-reading interview transcripts. The researcher is encouraged to immerse himself or herself in the transcript data (Smith et al., 2013). This may include listening multiple times to the audio version of the transcripts. To minimize errors found in transcription, the researcher initially went back and read the transcripts while listening along to the audio recording of the interview for each informant. To capture vocal nuances, speech cadences, and difficult accents the researcher listened to the recording of each informant interview transcript at least twice. Listening multiple times enabled the researcher to become grounded in the discerning the different personalities, subtleties in speech

patterns, inflections and emotions for each informant. This was followed by multiple readings of the transcripts and consultation of field notes. Accounts such as the chronology of events, the dynamic between interviewer and respondent, and informant perceptions of specific events for each person interviewed were added to field notes (Smith et al., 2013) The researcher began to note how the tone of interview moved from the broad and general to the personal and the specific (Smith et al., 2013).

**Initial noting.** Step two is the most detailed and time intensive portion of the analytic process, and if done correctly enables the researcher to develop rich textual themes. In order to prevent a superficial analysis through commenting only on what is expected to be seen in the text, Smith et al. (2013) recommend a careful and close analysis. Initial noting would include comprehensive exploratory comments. To accomplish this the authors recommended undergoing three approaches to create exploratory comments. The first was to read through the transcript and make comments describing what the informant has said. The descriptive comments represented the phenomenological component of IPA, and included relationships, events, processes or what mattered of the lived experience to the informant. The second approach was to read through the transcript and make comments referring to linguistic choices used by an informant. Word choices, the turn of phrase, repetition, and how an informant uses language (i.e. metaphor) in describing an experience helps to place the researcher closer to an informant's lived experience. The third approach is more interpretative and tasks the researcher with identifying more abstract concepts. The conceptual comments in the third approach involve shifting the focus to interpreting what the informant is discussing (the hermeneutic aspect of IPA; Smith et al., 2013; Vella, 2015). Conceptual coding may

take the form of questions (Smith et al., 2013). Conceptual coding is not about putting down answers, but opening up the analysis to different provisional meanings.

During the initial coding phase of the analytic process, the researcher created folders labeled “initial notes,” for each informant. The researcher read through each of the informants’ transcribed interviews three times. The researcher copied and pasted chunks of text from each informant transcript into their initial notes folder and followed with exploratory comments that included descriptive, linguistic, and conceptual notes. The second reading involved listening to the informants’ audio transcript of the interview for vocal inflections, pauses, and their expression of emotion and making additional notes to the exploratory comments. The third reading involved listening to the audio transcripts, reading the field notes, as well as reading the transcripts and making exploratory comments not included in the first two readings.

**Creating emergent themes.** Step three is to use both the interview transcripts and the data gathered from the initial noting to create emergent themes. Most of the work of creating emergent themes will be from analyzing the exploratory comments generated during the initial noting phase (Smith et al., 2013). During this step, a concise or pithy statement that represents the participant’s thoughts and/or words, and the researcher’s interpretations of those thoughts and/or words, is noted. In contrast to initial noting that is broad and loose, emergent themes attempt to capture an understanding that may not be specifically what a participant said, but reflected in actions or words of a participant (Smith et al., 2013; Vella, 2015).

In this study, the researcher created a separate folder for each informant labeled “emergent themes.” The exploratory comments for each informant were read and re-read

and emergent themes were created. The researcher would, as needed, re-read the interview transcripts, and possibly re-listen to the audio transcript to insure that the emergent themes best captured the informant's lived experience. The researcher identified between 22–32 different themes for each of the informants. The next step was to search for connections across emergent themes.

**Locating superordinate themes in each case.** Step four involves taking the emergent themes and searching for connections across them. Smith et al. (2013) suggested that not all emergent themes will fit into a larger superordinate theme. Those themes that are drawn together, like with like, can be merged into a superordinate theme. Some ways to organize themes into superordinate themes include taking themes that absorb others, that are the opposite of each other, that need to be placed in context, that serve specific functions, or that occur a number of times (Smith et al., 2013).

The researcher created a folder for each informant labeled “superordinate themes.” For each informant the emergent themes were cut and pasted into the new folder. From the emergent themes which were listed chronologically, superordinate themes were created from the emergent themes. Underneath each superordinate theme were listed its emergent themes. Between four to seven superordinate themes were generated for each informant.

**Moving to the next case.** Step five was to proceed to the next participant folder of emergent themes and repeat the process. To focus on the particular (the idiographic commitment) it was important during the analytic process to bracket any assumptions or expectations on the researcher's part from the previous participant's case, and engage each subsequent case on its own terms (Smith et al., 2013).

To do this in the current study, the researcher referred back to the linguistic comments that each informant used to create superordinate themes that attempted to capture each informant's unique experiences.

**Developing superordinate themes across cases.** Step six calls for the researcher to search for patterns across the cases and create superordinate themes. Patterns could include the number of times a theme appears, themes that are more potent, and themes of one case that can apply to many or all cases (Smith et al., 2013).

The researcher created a folder for the group labeled "superordinate themes." This folder included reference to the number of times a common theme appeared, and themes of a particular case that captured similar themes of other cases. Themes that appeared to be in conflict with each other were analyzed to see if there were an overarching connection, or were discarded. A final master list was developed of three superordinate themes and the supporting group emergent themes or thematic sub-categories. This list included similarities and differences for the informant group (Smith et al., 2013). This list was studied and revisited, always with the underlying philosophy to best capture and distill the themes that represented the informants' experiences as older African Americans living with HIV and a co-morbid condition.

This IPA process involved analyzing a transcript and resonating with parts in which a deeper and detailed reading of the part led to a more nuanced understanding of the whole. Recalling informant language, affect, and behavior in the interview session and immersing one's self in the transcript while simultaneously keeping an interpretative attitude of empathy and suspicion (to always be questioning) can make what Smith et al (2013) suggested as a "good enough" analysis.

**Summary.** The researcher used purposeful sampling and criterion sampling to assemble a sample of ten informants for this study. Recruitment was accomplished from flyers, snowball sampling, and recommendations from HIV clinic staff. Researcher initial contact with informants was by phone. Informants were given a demographic questionnaire and a semi-structured interview during the data collection phase. The researcher used IPA methods to conduct analysis of the data. The researcher created five folders to organize the data. The first folder contained the verbatim transcripts of the interviews. Transcription was done by the researcher and involved listening to an audio recording of each interview multiple times. The second folder contained the initial thoughts, which included exploratory comments that consisted of descriptive, linguistic, and conceptual/interpretative notes. The third folder contained emergent themes, which were a pithy and concise statement of researcher's interpretation of informant experiences. The emergent themes were culled from initial notes/thoughts and informant transcripts. The fourth folder contained the superordinate themes for each informant case. Superordinate themes were drawn from common or connected emergent themes. The fifth folder contained the group superordinate themes, that were assembled from informant common or connected superordinate themes, and was completed under the researcher's interpretative attitude of empathy and suspicion. Following the IPA guidelines for research analysis as outlined by Smith et al. (2013), the resulting product came from rigorous analysis by the researcher (Smith et al., 2013; Vella, 2015). Demographic characteristics were produced from analyzing demographic questionnaire. The raw data of the interviews was anonymized and transcribed by the researcher.

**Ethical considerations**

To the best of his ability the researcher attempted to address all relevant ethical issues before commencing studies with the informants. To prevent informants from being exposed to any known risks, the names and any identifying information of the informants for this study were disguised. Informants' names were coded, and the key for that code has been kept in a separate locked location from the interview data. In addition, all data from the interviews has been stored in a locked filing cabinet for up to seven years. Confidentiality has been protected for each of the informants. Every attempt has been made to protect the rights and welfare of informants. This researcher has strived to treat each informant with the utmost dignity and respect. A written consent from the clients was obtained. As part of the consent, all of the informants were informed that they were free to withdraw their consent at any time before, during or after the interview, and without the need to provide an explanation for their withdrawal. Additionally, the names of three resources were made available as a contingency for any of the informants seeking counseling, as result of negative emotional experiences, painful flashbacks, existential crisis, and withdrawal, resulting from the interview. Each informant received a ten dollar (\$10) gift certificate from Subway Restaurant for volunteering their time.



## Chapter IV: Results

### Demographic Questionnaire

Descriptive information for informants' demographic characteristics is shown in Table 1. These results are presented for three main areas, as shown below.

**Age, disease, status.** Of the 10 respondents (ages 51-72 years; mean age = 58 years, SD 6.738), all had a current disease status of HIV positive, and not AIDS defined, with a range of 7-27 years living with HIV or as AIDS defined (mean years living with disease = 20.8 years).

**Relationship status, sexual identity, and language.** Sixty percent of informants reported their relationship status as single (n = 6); 10% reported being married (n = 1), 30% reported being in a relationship (n = 3). Informants' sexual identity ranged from heterosexual (n = 7; 70%), fluid (n = 1, 10%), bisexual (n = 1; 10%), and none identified (n = 1, 10%). Most informants named their primary language as English (90%; n = 9). One (10%) was from the Caribbean and spoke a patois as well.

**Educational level and income.** Of the informants 10% (n = 1) had a middle school/junior high educational level; 40% (n = 4) had either some high school, a GED, or a high school diploma; and 50% (n = 5) with some college education. All informants (n = 10) had income levels under \$20,000.

**Other medical conditions.** Informants had other health conditions in addition to HIV. These conditions included neuropathy, COPD, diabetes type II, lymphoma, prostate cancer, osteopenia, glaucoma, hypertension, arthritis, heart disease, major depressive disorder, and PTSD.

### **Semi-Structured Interview**

Analysis of the semi-structured interview data revealed that informants explored their experiences of living with HIV and a co-morbid condition(s) through three super-ordinate themes: HIV as the new normal, HIV spurs self-advocacy, and health as a fragile construct. The first super-ordinate theme of “HIV as the new normal” illustrates the importance of how older HIV+ African American adults think about living with HIV years after being diagnosed. They experience this super-ordinate theme through exploring diagnosis as transforming the self, experiencing HIV as the new normal, and revealing for the male informants how their lived experiences instigates HIV trauma-induced lack of trusts.

The second super-ordinate theme, “HIV spurs advocacy,” refers to how older HIV+ African American adults experience relationships as grounding force and struggle with the push and pull of interpersonal relationships, learn resilience/making the best of the condition; and begin advocating for self.

Finally, the third super-ordinate theme, “health as a fragile construct,” describes how the women informants encounter female survival vulnerability, how informants navigate the psychological effects of HIV post diagnosis, and through their experiences with their co-morbid conditions come to view their health as a fragile construct.

### **Theme 1: HIV as the new normal**

**Diagnosis as transforming the self.** In contemplating their feelings, thoughts, and lives, older HIV+ African American adults, made reference to how diagnosis became a launching pad for serious and critical identity searching. Many came to learn that they were infected when HIV/AIDS was a fatal disease. Surviving long enough to benefit

from HIV drugs, these informants were confronted with existential questions. Aging and experiencing co-morbid conditions while navigating a new life with HIV spawned inquiry about who they were and who they were becoming. Diagnosis meant relearning self.

Mikey, aged 53, described: "...at first I got HIV, then I got the high blood pressure. Then the glaucoma came in. The diabetes came in and then the glaucoma. I was like dealing like I was [a] piece of puzzle. I started trying to put my life back together like a puzzle."

Mikey's experience stating that "I was [a] piece of puzzle" suggested that he was at one time whole and had become fragmented, and that he had to now try and re-assemble the parts. The process of finding out who you are in light of the diagnosis is where the transformation began.

Pepper, aged 51 asserted that "...being newly diagnosed with HIV at the first stages of it, you don't really know all the things that...you're a brand new person. You going to have to learn yourself all over again. And it depends on what type of person you are that's gonna keep you grounded."

Informants' language of "I was [a] piece of puzzle," or "you going to have to learn yourself" suggested an awareness that their conception of the "self" had to be re-oriented to a new post-diagnosis reality. But implicit in transforming to the new self is the necessary passage of time. To reassemble the pieces or "learn yourself all over again" denotes a process. With most of the informants having been diagnosed over 15 years ago, when they were in their prime, their new emerging identity had to incorporate aging and the onset of age-related co-morbid conditions with HIV acting as the catalyzing agent.

**HIV as the new normal.** With the passage of time, older HIV+ African American adults began to adjust and accommodate to the virus and their experiences of HIV became normalized. As more potent HIV drugs became available, and the deleterious effects of HIV were minimized, informants described in an almost mundane manner the nature of their day to day lives.

Merle, aged 64, opened by reporting, “I just look at it as HIV is normal. I live with it, it’s a medical condition, it’s normal.” Within this extract are some salient issues to note. Merle describes HIV as a medical condition and that it is normal. Her tone and affect in the interview reflected an attitude about HIV as something serious but not life threatening. Merle mentioned that she had anemia as a young woman, which went away once she experienced menopause. Her experience with anemia informed her relationship to HIV as she stated, “...that’s it, but otherwise HIV I just take [it as] it is—like when I was young and had anemia.” Merle’s experience with anemia was to endure it, treat it, and live with it until she aged out of it. Because she lived with anemia for much of her life, it had become her norm. This suggests that other potentially serious and life-long medical conditions such as diabetes and hypertension are considered normal; that implicit within this normality are that serious diseases are a regular part of life.

Similar to Merle, Alva, aged 55, responded to an inquiry about her feelings when she takes her medication for hypertension and HIV explained, “The HIV is different, I be normal with it. It don’t really bother—it just my asthma, just stuffed up...” In this extract Alva contrasts her experience of taking medication for hypertension, with her interaction with HIV and the medication she takes to treat it. Where she had expressed concern about keeping her hypertension under control, she described her interaction with HIV as

different, and by contrast to hypertension, as normal. Further, she described the dynamics of her relationship with HIV as less serious than her asthma, more of a minor inconvenience. One can infer from the statement “it don’t really bother,” that she is not distressed or distracted by HIV or by HIV medication.

Mikey, aged 53, compares himself to non-infected people saying, “I go through the day like everybody, a normal person, I just got HIV. You know, that’s my biggest peeve. But other than that I try to exercise, eat right—you know—go on with my day like everybody else. You know it can be done, it really can be done.” In describing his day Mikey twice says “like everybody,” employing the language of comparison in referring to himself in relation to others, to assert his normalness. Additionally, using the descriptor “pet peeve,” Mikey evokes images of something that is merely an annoyance when referring to HIV. Implicit in his declaration “you know it can be done, it really can be done” is that his life is normal because he has not allowed HIV to detract or distract him.

Similarly, Roosevelt, aged 65, described his day-to-day experience, “I never think about it...not just being HIV. It’s – I wake up, I do the same thing. I may have cup of coffee, I watch TV. If I have an [medical] appointment, I take care of that. That’s about it, nothing special...” In this extract, note how Roosevelt asserted that his experience of HIV as a ubiquitous presence in his life goes without conscious notice (“I never think about it”), and yet he identifies himself as “being HIV” rather than having HIV. The implication being the virus in his body is such a constant presence that his identity and HIV have merged. His identity revealed in the statement “not just being HIV.” He clarified, however, he does not think about himself in that context, but discussed in detail

the almost mundane nature of a morning routine, ending with an appeal to his normalness with the statement, “nothing special.” “Normal” as a descriptor by Merle, Alva, Mikey, and Roosevelt, suggests that it is not out of the ordinary and has been so incorporated into their daily life, that it is barely noticed. HIV medical care, which includes regular trips to the doctor, sometimes complicated medication regimens, and the frequent blood labs that are drawn, appears to be absorbed into the construction of daily rituals that informants maintain over time. Even though it is an inconvenience, the routine of living with and treating HIV is no longer viewed as a disruption.

**HIV trauma-induced lack of trust.** Almost all of the men discussed experiencing some kind of HIV trauma that compromised their ability to trust. The trauma is living with the disease itself as well as experiences connected to having HIV. While all of the informants made reference to fear of stigma, it was specifically the men whose traumatic experiences translated to trust issues. Men spoke of concerns about confidences and consideration that other friends and family members would keep, that medical providers would honor, and that other HIV+ men would respect. Male informants’ fear of being outed with HIV or concern of being mistreated because of HIV sometimes translated to extreme anger, withdrawal, and social isolation; all resulting in attitudes of suspicion, circumspection, and mistrust.

Mikey, aged 53, explained, “You know, society has been taught the wrong things about people with HIV... So you see a lot of people getting beat down, beat up, or getting shot behind this. So that puts me in a very paranoid state, of family members if they find out, they leave you. They stop talking to you, they don’t want you around and stuff...I isolate myself from everybody. You know, and that’s something I don’t want to do.”

Mikey's experience of HIV-related trauma was seeing others who were infected attacked physically or forced to become outcasts. His extract underscores that his caution, fear and resultant social isolation are not only byproducts of a desire to protect himself from physical harm, but also the consequence of realizing that opening himself to significant others [e.g., family] brings the risk of rejection. Keeping everyone at arm's length is also his way of preventing emotional harm. But even as he admits to practicing his own social exile, he is equally clear that this is not behavior that is part of his ontology; the inference being he has no choice, and he is powerless to change this reality.

Mark, aged 57, spoke of his frustration with and distrust of HIV medical providers at a city hospital. "They had another patient in the room, then they talking about the HIV and stuff. How did you get it...blah, blah, blah this. And I said 'Don't you know that's against the law what you're talking about? You're disclosing stuff this person ain't got no business listening to.' 'Well, why you come here anyway' [the nurse asked]. I said-I said, "You know what, I'm surprised people come in here...."

This traumatic experience of being outed provoked feelings of anger that he expressed during the interview session. He described that after that incident he was vigilant when meeting with doctors, gauging their attitude. He shared that this experience has kept him suspicious when he meets with doctors, "Some of them [doctors] come in with an attitude, and try to take it out on the patients...you know how you get the feeling they don't really want you there. You know you get that feeling. See I been around enough, I was raised in the streets."

In the extract that Mark compares his experience with medical providers to being "raised in the streets." The inference of both experiences is that he needed to be cautious,

hyper-aware, and not trusting. The streets were not safe, and from his experience of being outed, neither were hospitals and doctors. Mark's choice of language conveys the emphatic nature of his feelings on the matter; with the words "been around" having dual meanings. He uses "been around enough," first to signify that he has lived/existed a long time, and second, to assert that he has been in close proximity to enough of the danger and threats, to be aware what life is like in the streets. One meaning that may be inferred is that he has lived long enough to know with some authority, from being "raised in the streets," that when "you get that feeling," it means he has honed his ability to feel when he is safe or not safe. The other meaning that may be inferred is that being "raised in the streets" has enabled him to see a lot and experience first-hand what it feels like to not be wanted.

When asked about the support system that he seeks, Cory, aged 52, commented on not trusting his fellow male HIV survivors for support. "And here I am trying to find myself with the society I live in, and I just don't know how to say 'no thank you.' Because I rather not have the support group, then have them come around. [If I] want some more pain-I can get it for free." In this extract, he is referencing struggling with saying no thank you to the substance abuse, risky sexual behavior, and personality conflicts that he has encountered within the social circle of other gay HIV-infected Black men. His trauma came from his sense of dislocation exacerbated by the attempts to "find myself" within this community, and being met with the temptation of more drugs and sex, rather than the emotional and psychological support that he craves. This prompted his comment, "... [If I] want some more pain-I can get it for free." To protect himself Cory asserted that he kept himself separate from other HIV+ adult survivors. Because of



the perceived lack of support from other gay Black male HIV+ survivors, he had adopted an attitude of wariness and suspicion toward them.

## **Theme 2: HIV spurs self-advocacy**

The more that HIV+ older African American adults began to acclimatize to living with HIV and age-related co-morbidities, the more they began to make positive efforts to improve the quality of their lives.

**Relationships as grounding force.** Almost all of the co-informants discussed how they explored personal relationships (i.e., family relationships, support group relationships) as a way to enhance their own well-being. Although some share moments of frustration and anger that were imbedded within personal relationships.

*Family relationships.* Merle described what her future would look like for her. “The future...being a grandmother now. I look like, uh I mean I look after giving gifts and things to the grandkids. I don’t party no more, I want to go on... I don’t do the things I did. I try to give some advice...that’s it.”

Merle makes reference to stepping into the role of matriarch in “being a grandmother now.” The future means not only assuming the identity of grandmother, but concomitantly giving up certain kinds of behavior (“I don’t party no more”). For Merle sobriety is a necessary component to be able to fully interact with the grandkids (“giving gifts,” “give some advice”). The role of being a grandmother helps her to establish her priorities (“I don’t do the things I did”) and gives her the space to try and be her better self, as she commented, “I want to go on.” With something outside of herself representing something to care for, Merle is able to change her addictive behaviors (i.e.,

getting high, drinking to intoxication). Relationship with her grandchildren helps to ground her and connect her to family.

Similarly, with regard to family, Mark asserted that “my wife keep me going. Okay, huh, and my daughter. And now I got J, she got, she got a kid and so she want me to be the god-father, so. And that-that keep me going so...being with all that.”

Family and Mark’s connection to them are one of his motivators to “keep it going.” He says the phrase “keep it going” several times in the interview to underscore his tenaciousness. His connection to his family and his desire to be there for them inspires his tough mental attitude and his unwillingness to surrender his mind to negative thoughts or feelings of hopelessness. Mark is one of several informants to comment about a fellow survivor who committed suicide. Although he was very specific in repudiating suicidal ideation, Mark also mentioned his wife and daughter’s admonitions for him to watch his health, as the powerful extrinsic motivators to keep him engaged with his general health and HIV-related medical treatments.

Informant Alva asserted the sense of personal satisfaction she derived from family relationship by declaring, “...I’m happy with my life. My son is back in my life, like I said. I have a grandbaby. And my niece, I love her to death, she went over to her future husband...and I said [to her] I’ll probably get married before you, and I did. And—uhm, and you know I just be there to support them.” Alva’s affect and demeanor lifted as she discussed her family and her new husband. When she struggled with substance abuse problems, her addictive behaviors allowed significant relationships to wither and wane. She was imprisoned and lost touch with her son. When she was diagnosed with HIV while in prison, she resolved to fight her addiction and re-establish contact with

significant people in her life, specifically her son. Her desire to support and care for her family endowed in her the sense of purpose necessary to recover from her addiction and remain engaged in HIV-related and general healthcare.

*Support group relationships.* Eddie, aged 56, commented about his involvement with support groups and how relationship with other HIV-infected survivors are important. “For one thing I like to be around people. And people that’s sharing and talking about their day. They pass what’s going on with family, or whatever, I like to hear that stuff, you know. I got something going on with my family, that’s going on with me...you know stuff like that I like to get off my chest and talk about it. Maybe I can get some help from you, maybe I can get some help from her.”

As an older adult confronted with co-morbidities and adjusting to aging, Eddie’s interaction with support groups is comprised of the exchange of knowledge, emotional and intellectual, that help provide him with perspectives about how to live better as an HIV-infected person. He seeks comfort and draws inspiration from peers of similar circumstances who have found a way to live or succeed in spite of the hardships. Like Alva, Eddie’s life has been challenged by substance abuse issues, and he has sought support from other adults fighting for sobriety. He has learned to advocate for himself by interacting in community. Whether it is a community of recovering addicts, adults living with HIV, or, in his case, both, he has been intentional in seeking out others to whom he can relate, as he tries to enhance his quality of life. Eddie declared, “I have to have support where somebody is talking some real good stuff about how to live, and what life is about, you know, this and that.” Insight received from shared narratives help to ground him.

Mark, Alva, Merle, and Eddie were diagnosed when HIV was understood to be a fatal disease. Living as long-term survivors of HIV, and facing co-morbid age-related illnesses, these informants, conscious of their own mortality, began to realize the importance of relationships, and through relationships became intentional in their actions to monitor and maintain their healthcare. However, their healthcare notwithstanding, some of the informants remarked about the difficulty of some of their personal relationships.

**Struggle with the push-n-pull of interpersonal relationships.** Ruth, aged 72, who projected a happy-go-lucky persona reflected on moments when she was hurt in personal relationships. Describing her day-to-day experience in interacting with others she commented, “Because people ain’t carrying or feeling your pain. You are. And some of them just don’t understand. They say, you ain’t hurtin’ that bad. Then you want to say something to them, and it could be disrespectful. But in my head I keep it there.”

Ruth reported that it was difficult to communicate with others. Getting people to understand can be a challenge. She described keeping a smile on her face, and displaying a happy, friendly personality but feeling that at times she did not want to interact with others. Although she was reluctant to call people out on their lack of empathy, she reported feeling dismissed. The pain of having others brush aside her suffering stirred angry feelings.

Cory referenced his frustration with identity politics with support groups. “I like to go over to some of these groups, or be a part of my community as far as Black men dealing with HIV or just gay. And I try to go fit in there. And you get this Stepford wife mentality going on. So I don’t feel comfortable there.” Cory expressed concern that

opening himself to others within the group ends up fostering certain assumptions. [“They lock you in with a certain crowd.”] He feels uncomfortable in company of other men who identify a certain way, and imply that he is expected to conform to a certain identity. If he differs in his opinions/beliefs, he is punished. [“A guy in a position to help...already assumed I was arrogant.”]

Alva commented that her frustration happened whenever she had to stand in the middle of tension that occurred between her adult son and her new husband. “And at first he [said he] didn’t approve of me telling him I’m fittin’ to get married. But he said ‘momma that’s your life, you got to have a life.’ He said ‘I don’t have to respect him, but I got to respect you.’ So I said ‘Okay, but when you’re around him, I would like for you to respect him as much as you respect me... ‘But momma I’m grown now.’” Navigating relationships between her new husband and her son was important to Alva because she wanted to model for her son what it is like having a positive relationship with a significant other. She mentioned [“You got your little family now. And now I wish you stay with her for the rest of your life, and don’t have babies out here by other womens. I want you to be different (from me).”]

**Resilience/making the best their condition.** Older adult HIV+ African American living with co-morbid conditions have found positive ways to navigate the effect of aging and the daily challenges with illness. Some of the informants confront each day living with multiple marginalized identities being: African American, female, older, HIV+, of low socioeconomic status, gay or bisexual. Even as they experience hardships directly related to those identities, they have found ways to persevere. Ruth recognizes her declining health, aging with HIV and age-related diseases, but resolves to

make the best of it, saying, “And there are definitely some problems, could be opportunistic infections. And all of them [HIV-related infections] could come in like that, so that’s helping me take better care of myself. The osteo[penia] and arthritis to me, means like at 72 years old, okay—I can slow down now and have reason to... I don’t have to run no more. I can take my little cane over here, I can take my time now walkin’ down the street. And I see a lot of stuff on the street, a lot of signs that I missed ’cause I was walking too fast...out there trying to get to somewhere I shouldn’t be in the first place.”

In this extract, Ruth reframes her physical limitations as giving herself permission to slow down, and take the time to appreciate things around her. Her awareness of her advanced age, precarious health, and the nature of opportunistic diseases spurs her to be more proactive and vigilant about taking better care of herself. In spite of the physical challenges of walking with arthritis, osteopenia, and neuropathy, Ruth’s resilience is apparent as her diminished vigor does not deter her from spending an entire day traveling to go to doctors’ appointments or shopping for food. “...If I miss a bus, if I was trying to walk and get to the bus stop, if I miss it that means I don’t have to rush and catch the next one. Take my time and cross the street, sit at the bus bench and listen to the madness out there...” With her advanced age comes a sense of patience about the limits of her abilities. She reflects ironically about “the madness out there” and how she once participated in it, “...I see a lot of stuff on the street, a lot of signs that I missed ’cause I was walkin’ too fast.”

As Ruth has aged she has been able to take the time to reflect on her life in the past and her life at present, and assess her attitude about herself in light of her current

functioning. As the oldest of the informants, she was among the more resilient commenting, “That’s how I will get older in life is by not looking at things so seriously. Look at things on the bright side, you’re still here. You feel, you hear, you see, you can think.”

Similarly, other informants have examined their mindset about their health challenges. Pepper, diagnosed with spinal cord and joint disease, and arthritis, commented about his physical limitations saying, “...It’s hard to tell the difference. So you kind of throw it all in a bag and deal with it. Because if you have more than one diagnosis, it’s hard to tell which feeling is coming from each diagnosis...so it’s kinda difficult. But if you a positive person you kind of adjust yourself and be positive about everything because this... this situation is what it is.” Pepper acknowledges the nature of his health concerns but is able to exercise some influence over his limitations by psychologically not ceding control of himself to negative cognitions. He speaks of a shift in his perspective (i.e., adjust yourself) that accepting the unchangeable nature of his HIV status or his co-morbid conditions does not entail acquiescing to feelings of hopelessness or helplessness. His attitude suggests whole body health is not only determined by one’s physical state, but also affected by a person’s mental state.

*Emotional resilience.* Mark described how his mental state about HIV has informed his interactions with other male survivors. “I tell some of the guys here, you know—they be talking about it, and I go and say you know what man, you need to let that stuff go. You know what you got, you got to deal with it. Just deal with it.” Mark admonished the other men for ruminating about their condition. Like Pepper, Mark shares the philosophy that whole body health does not reside only in the condition of a person’s

physical state, but also their mental state. Earlier in the interview Mark shared his philosophy to not surrender to stress. His resilience is encapsulated in the statement, “No matter what’s in your way, you can’t stop—keep on going [and doing] what you gotta do.” He acknowledges the HIV, but resists engaging in conversations that validates depression. His mental state is not denial but resisted acceptance.

When asked how she coped, Merle spoke of making the best of her condition: “I read a lot of booklets about HIV. I’m still learning on this, even after 19 years, it took me 19 years...” Coping for Merle entails learning as much as possible about HIV. Implicit in her statement, “it took me 19 years,” is the notion that living with HIV is an ongoing learning process. Curiosity about her condition and understanding her body, means acquiring knowledge that gives agency. Her ability to get informed began when she was first diagnosed. She remarked, “... I was mad. Because I didn’t know what kind of disease this was. I didn’t panic I went to the library to learn.”

Roosevelt, described how he was intentional about not living with regrets and was reconciled with his life. “I don’t even go there, I just let it go out the window and go right back and go forward. That’s how I am—that’s how I am. You can’t spend, I feel, the life I have left basically [not] content. So if it’s not broke, why fix it.” Roosevelt does not view his life as something in need of repair and consequently pushes negative thoughts out of his consciousness (i.e. let it go out the window). He has made peace with his condition.

**Advocating for self.** In making the best of their condition, informants Mikey and Pepper began taking steps to be more intentional about improving the quality of their lives. Mikey responded to a question about how his feelings have changed since his



diagnosis, commenting, “But now that I’m HIV+, got glaucoma, I got neuropathy, I got high blood pressure, I try to get out there and walk. I walk, I walk. You know shoot...I live on one end, I live on 74<sup>th</sup> ...she [his girlfriend] live on 94<sup>th</sup>. Why you walk then? [she asked] Cause I love to walk. You know, it’s good for me, it’s real good for me.” Once Mikey came to reconcile with his condition, he felt responsible to others (i.e., his girlfriend) and became more accountable for his health. But despite some of the physical limitations imposed upon him by some of his co-morbid conditions, walking represented his change in his attitude. What could have been perceived as an onerous or burdensome way of transportation is reframed as something that frees him. Mikey shared that his girlfriend did not like to walk, and when she asked him why he did, he asserted with enthusiasm, “I love to walk.” His mentioning walking four times in one sentence suggests his commitment to live more proactively. The inference is that walking is his way of taking back control from his illnesses.

Recognizing that anxiety and depression are common co-morbid conditions that accompany HIV, Pepper asserted his control over his conditions, commenting, “...it’s been like a maintaining situation. Going through the process of maintaining, eating right, taking your medicine right, and cleaning house getting’ rid of all negativity.” Pepper uses the metaphor of the body as a house that has to be carefully maintained. He advocates for keeping his house repaired by not only “eating right” and “taking...medicine,” but also understanding that part of the maintenance is psychological, and “getting rid of all negativity” suggests purging himself of the negative cognitions that could wear and tear on the psyche. Pepper’s awareness of mind–body connection was summated, “So I’m

trying to stay positive because the more you feed on negativity the worse the situation be.”

Ruth projected a positive attitude as she described being self-reliant, and fighting as a senior citizen to keep her autonomy, commented that she was vigilant about surrounding herself with healthcare and social service professionals. When asked about the future she responded, “It looks good to me, because I’ve used a lot of ....did a lot of researches, surveys. I been to a lot of women’s groups, 50+ [year old support] groups, I have a therapist I talk to, I got a good doctor. Plus I got a lot of triage nurses and friends who care. And I now kind of like have my ducks in a row. Where if anything were to occur that I could not handle, I believe that there would be someone there to help me go through this.” Ruth’s efforts to build her own support network enabled her to live a life of psychological independence. Because she advocates for herself advanced age, HIV, and co-morbid conditions are not sources of anxiety or worry.

Mark commented that to prevent worrying about his condition, “...I do cooking, I draw pictures, and stuff. When I don’t do that, I started working on uh-remote control cars...yeah. Basically yeah. Keep your mind off of things.” By finding things to occupy his mind he is able to function better. Cooking and drawing were behaviors that enabled him to share something of himself with his wife, daughter and others. However, for himself, building remote control cars was something in which he prided himself. He described showing children how to build cars, and recalled building and selling some of his remote control cars to collectors. By finding an activity in which to immerse himself, Mark not only is able to distract from temptations to ruminate about his health, but also is able to remind himself that he has a skillset that brings others pleasure, him a small

amount of remuneration, and that ultimately reflects positively about himself. It is his small way of being something other than the HIV-infected older man.

Like Ruth, Pepper, and Mikey, Mark had resolved to take action that would benefit his mental and/or physical health, and not allow HIV, co-morbid conditions, and age to impede his pursuit of a quality life.

### **Theme 3: Health as a fragile construct**

The super-ordinate theme of “health as a fragile construct” captures how all of the informants, in light of aging, surviving HIV and living with various co-morbid illnesses, were constantly challenged by the vagaries of health. Health, for the purposes of this study, includes emotional, psychological, as well as physical well-being. Women informants shared how they experienced acute feelings of vulnerability that continue to be an indelible reality of their lives. Informants spoke of psychological struggles they encountered post HIV diagnosis.

**Female survival vulnerability.** All of the women informants discussed that after diagnosis they began to have experiences where they questioned their attractiveness, their capacity for autonomy, and expressed fear that ahead of them lies a future filled with loneliness and isolation. As a single mother, Debbie, aged 51, described her life post diagnosis. “It happens too fast. I thought it out, before I had this pain in my feet, I was going to be able to work, save some money—you know do something for myself. It like crumbles, it’s like hard. It’s the only way I could explain myself. I’m tryin’ to explain it the best way I can. It’s so hard, it’s really stressin’. It’s like, I don’t like...there’s no future.”

In describing her dilemma, Debbie struggled to convey the depths of the emotional trauma she experienced at the loss of her ability to work, to sustain herself, and to provide for her future. Debbie's origins are from the Caribbean, which helped to provide the context for her trauma. Working hard and saving for herself and her family were cultural norms that she internalized and brought with her when she emigrated to the United States. She shared that in her culture people aspired to build a house. She had been diligently working to save to build a cement home back in her country, before she was diagnosed. Having her house in the Caribbean symbolizes stability, having an asset, something to secure her future, "to make good." A house was the way she knew to create income, wealth, and to be an anchor for to be able to plan and provide for her future. HIV and the co-morbid conditions impaired Debbie's ability to continue working, and killed her dream of home ownership. Without a source of income to sustain her in her retirement, she expressed feelings of despair commenting, "There's no future."

Unlike the men who reported that they tended to withdraw when feeling vulnerable from negative experiences of HIV and/or co-morbid conditions, female informants shared moments when they feared being isolated. When asked about barriers she encounters to feeling better, Debbie shared her fear of what may happen if others discovered that she is HIV+. "So where can I find me a good man? ...it's going to be hard for me to tell them...if I tell them, then they don't want to be with me. So that's my biggest barrier right there, so that's the biggest barrier for me – loneliness."

Ruth recounted a moment of dread when trying to contact one of her HIV-medical providers. "And I called somebody over here. Couldn't get nobody to talk to, over here. That make it worse...because I say ooh wow. If I could just get a voice from the outside

to talk to, I'd feel a hell of a lot better." Ruth prided herself in being resourceful and independent. She mentioned that all of her providers knew her history as an active and independent person. So if she reached out to them, it had to be something that was causing her significant distress. Not being able to contact providers forced all of her insecurities to the surface. She declared "So yeah, the pain does get pretty depressing sometime, and I do feel isolated sometimes. Also, I do feel like...sometimes maybe I feel like nobody don't care sometimes." She portrayed her distress as not being rooted in her pain, but in feelings of abandonment; the inference being that emotional pain is experienced as acutely as the physical pain.

When discussing aspects of her illnesses that are barriers to her feeling better, Merle responded, "—other people's illnesses. I'm going to get nervous thinking I'm going to get that. 'Cause I have HIV, I'm thinking I'm going to be getting the symptoms." She shared that in the late 1970s because of her anemia she contracted HIV from a blood transfusion. Merle discussed that as she has gotten older she has become hypervigilant about monitoring her health. She expressed worry about "what's going to be coming to me." As the youngest of her siblings she discussed witnessing their decline from aging, getting ailments, losing their faculties (i.e., hearing), and becoming wheelchair bound. Merle expressed fear that as the only one in her family to have HIV, she looked forward to a future of debilitating illness and increasing struggles with aging. "I'm lookin' forward to that, I don't want to die. You want to die? I would love to get 102, but they [siblings] look so bad, ha-ha-ha."

For one of the informants having a sense of agency, a way of making her way in the world unencumbered, was constantly threatened. Alva commented how she

experienced vulnerability related to fighting for her sobriety. She remarked that the reason she relied on her support system is “to keep me clean, one thing. And if I don’t [go to see my sponsor] I’m a go use. Like I said, ‘The devil he be working. He’ll tell me go down the street, go show off. You got a little weight on you, you got a little money. I can get you a nickel.’ Off and running I go. I choose not to go back to that area...”

Alva describes her addictive behavior as “the devil he be working,” the malevolent force that is trying to get her to surrender to her cravings. She noted that even as she began to experience some success with her sobriety (e.g., gaining weight, saving money) the temptation to use strongly remained (“get you a nickel”), and she could not visit friends and acquaintances and share her success with them because they lived in the neighborhood where the drugs were. Being vigilant to prevent the threat of relapse consumed a good deal of her mental and physical energy. She spoke of getting up to attend 6:30 a.m. drug support meetings. Her struggles with substance abuse was a constant that had to be negotiated around in her marriage. Alva commented that she and her husband had to collaborate to help keep her appointments with her HIV medical provider and to attend narcotics anonymous meetings. Resisting the pull to indulge in substance abuse, and navigating HIV and co-morbidities (i.e., hypertension, asthma) was and continues to be a daily challenge for Alva.

**Psychological effects of HIV post diagnosis.** Older African American adults living with co-morbid conditions reported various experiences that impacted them psychologically after being diagnosed with HIV.

Ruth noted that shortly after she was diagnosed HIV, her relationship with her significant other ended, and she began having other health problems. She described her

reaction to that confluence of events as, “Uhm, that’s the time it got unbearable. Because for those two years I got on crack. I’ll be honest, I got on crack, I started smoking crack for two years. And all that, Dr. \_\_\_\_\_, PI nurses had put together for me to come on up and deal with the situation, and make uh...you know the t-cell count right, it all went down the drain, down the hill.” Her issues with substance abuse were a direct consequence of her struggles with adjusting to being diagnosed with HIV. She admitted that she struggled with loneliness and with managing the disease by herself. Drugs became the coping mechanism to help her adjust to the severe life changes. However, the coping mechanism became “the really, really, big gorilla ridin’ my back...” The work she had done of raising her immune system and reducing her viral load through ARV therapy and regular checkups, had been reversed.

Debbie shared the depression she experienced post-diagnosis. She did not tell her adult children about her diagnosis, nor did she tell young niece, who was living with her. “She [would] pass through the living room to use the bathroom. And she don’t know [about me]. She say, ‘I come here (bathroom) so many times...I’m sorry, I’m not sleeping. And I’m crying, and she asks me ‘Why are you crying?’ I don’t know what to say...” Because Debbie has kept her HIV status secret from members of her family (niece, children), the burden of keeping the secret has been so emotionally debilitating, she would go to the bathroom to cry. Being discovered in the bathroom by her inquisitive niece served to heighten her depression as she was caught in a conundrum of having to keep the secret, and despairing as she did.

Commenting on the reality of being diagnosed with HIV and hypertension, Roosevelt explained, “I’m learning what loneliness is and I don’t like it, I don’t like it at

all.” His lived experience of HIV and hypertension has meant compromised health, and discovery of profound feelings of isolation.

Summarizing his life, Cory referred to HIV as a “chunk.” “It’s a chunk in my life that I have to deal with. Where others are getting up and having a normal day. And they can go just—you can go on a date with somebody if you’re not HIV positive. You’re not worrying about how you’re going to tell this person if you all like each other. You’re not so much worried about uh-uh you know, different stigmas. Uh, you’re able to think about having a family and kids.” HIV is a “chunk” or psychological block that inhibits him from imagining a life with a significant other. The inference is that a person who does not have HIV does not give thought to stigma, or having to reveal a secret, and can think about having a family and children. Once he was diagnosed with HIV he believed he surrendered all chances for a life of normalcy.

**Health as a fragile construct.** Informants reported the effects of declining health, physical enervation, and associated daily challenges of managing multiple illnesses. An oft repeated theme was difficulty managing medication.

Cory: “And so if I can get over the lump of the nausea in the morning, or the-how do I say, drowsiness and dizziness, of the rest of the medications, I usually have a normal day.”

Alva: “...Sometimes if I get sick, I go back to the doctor, and they might add another one. But I told him I can’t keep taking all these different pills...I was taking 13 and 14 pills, but now it’s down to at least 9 or 10.”



Eddie: "...I have feelings about if I don't take my medicine, I feel guilty....If I don't take my medicine, so I'll try to rush and take both of them before the night is up. And it's really not good like that."

Debbie: "And it's like too much medication to take at one time, so I do what I do. I take the high blood pressure pills in the morning, the pill for the pain...the arthritis in the morning, you know, and then I do what I do in the nighttime, I take my HIV pills."

Informants shared how they struggled with medication fatigue, and how even, at peril to their own health, took an occasional holiday from their medication regimen. Some remarked about how the cure was at times as rough on their bodies as the disease. Guilt, frustration, and depression were constant companions that participants wrestled with as they contemplated the idea of a lifetime of tolerating the effects of sometimes toxic medications.

Some commented about the daily grind of living with co-morbid conditions:

Debbie described during the interview, "Right I know that my high blood pressure is up. I got this headache, my head aches right now. I just got out of the bed this morning because I know I have to come here and do this interview with you. And I wanted to do it. But really it's hard, it's very, it's very...day to day living is very hard."

Ruth shared how her body is slower because of her co-morbid condition. "And the feet, neuropathy, the neuropathy in the feet causes numbness. And when I get to get ready to get up and walk, I have to be careful getting up, my feet get numb and my ankles get crazy. I don't want to kill over and break the ankle..."

Participants report how co-morbid conditions, the diseases that are concordant with aging, as well as diseases that are a direct outgrowth of HIV, take their toll on the bodies and increase the debilitating effects of aging.

Pepper mentioned that when he takes his medication, he is reminded, “It’s kinda...it lets you know once you been diagnosed with neuropathy or arthritis, or lumbar spinal and joint disease. It kind of slows you up. I noticed that I’m slower than I use to be. When it come to walking, when it come to running, so it’s a change...I’m looking at is as I’m a grandpa. I never thought I would be a grandpa -ha, ha, ha. ...I’m older and I’m a grandpa, I’m at grandpa age.”

Pepper commented on losing his vitality and compared his current physical state to being a grandpa. Arthritis, neuropathy, and lumbar spinal and joint disease are all joint and neurological diseases that can manifest physical effects similar to someone with advanced age. Slow walking with a cane, body stiffness, shuffling gait, and shaking are symptoms that clients have displayed or reported that were products of joint and neurological diseases. Pepper who was the youngest of the participant-researchers was at times afflicted with symptoms that made him among the least able-bodied.

Some of the informants commented on the discomfort of living with co-morbid conditions:

Eddie described his neuropathy as “like thunder and lightning going through your legs...you’re walking on a nerve. So that’s what I deal with the neuropathy, the cramping is real bad.” Similar to Pepper, Eddie’s capacity for mobility is compromised. When he is struck by painful cramps from the neuropathy, he commented that the neuropathy was worse than the HIV.

Mikey asserted how “the diabetes is damned if you do and damned if you don’t. If it’s too high you can go into a coma. If it’s too low you can go into a diabetic coma. To get down to control, I got to watch what I eat, and that’s kind of hard for me.

Mikey struggles with the deleterious effects of diabetes mellitus. He was diagnosed with glaucoma shortly after his diagnosis with HIV. Because of the HIV, to get his sugar levels stable, he reported he struggles to maintain the delicate balance between too little and too much.

Mikey’s challenges with his co-morbid conditions, like the others, was experienced more acutely because of HIV. Eddie and Ruth’s neuropathy is a direct outgrowth of HIV’s degenerative effects on the nervous system. Pepper’s spine and joint diseases, and Debbie’s hypertension are more challenging because of the presence of HIV in their bodies. The co-morbid conditions, and by extension, the mental health concerns, result from HIV’s toll on their physical and mental resources.

Implications for these and other health challenges as well as suggestions for addressing them will be explored in the discussion.

## **Chapter V: Discussion**

Three super-ordinate themes emerged from the exploration of informants' experience of living with HIV and a co-morbid condition(s): "HIV as the new normal," "HIV spurs self-advocacy," and "health as a fragile construct." Embedded within these super-ordinate themes was the notion that aging, navigating comorbidities, and surviving with HIV and/or AIDS were inextricably intertwined, and how informants psychologically and physiologically experienced their conditions. Key points related to the three super-ordinate themes will be addressed in the discussion section to follow, as well as possible implications for future research and potential interventions that may provide new directions to help adults cope with HIV/AIDS and co-morbid conditions. Folded into the discussion will be references to extant literature and relevant theoretical concepts.

### **I. HIV as the new Normal**

Informants recalled how their lives were altered immediately after receiving their HIV diagnosis, and discussed how their lives have changed years after living with the reality of having HIV. A majority described early struggles of reconciling their identity to the experience of living with HIV. The onset of co-morbid conditions such as hypertension, diabetes, and cancer created a synergistic storm when experienced alongside HIV. Employing language like "puzzle" or "pieces," informants shared how their identity after HIV diagnosis had become fragmented. Burton (2012) in his phenomenological study of the experience of stroke victims resonates with a similar theme of reconciling with embodied change. Some in this study were diagnosed late in disease progression and had AIDS, where their physical health was severely

compromised, not unlike a stroke survivor. The aging and introduction of co-morbid conditions exacerbated health decline. Although the introduction of anti-retroviral therapy ameliorated the lethal effects of HIV transforming the virus from a fatal disease to a chronic condition (Scandlyn, 2000), informants had to re-orient themselves to the new post-diagnosis reality. Green and Smith (2004, p. 20) characterized this experience as “a shift from the acute mental health problems associated with dying to the chronic complex problems associated with living” (as quoted in Flowers, Davis, Larkin, Church, & Marriott, 2011). For example, one informant from this study commented that “you’re a brand new person...you going to have to learn yourself all over again.” Re-learning yourself post-diagnosis is a process and denotes the passage of time. This process is the starting point for transforming the self.

Informants over time began to adjust and accommodate to the virus, and reported how they experienced HIV as something “normal.” Taking daily dosages of HIV medication, enduring regular medical checkups, and blood lab work had been portrayed as a part of their “daily routines,” like a morning cup of coffee, or watching television. Descriptors like “medical condition,” “nothing special,” “never think about it,” and “biggest peeve,” in reference to HIV, served to neuter the effects of the disease on the lives of individuals. Day to day experiences with HIV were perceived by many as no more than an inconvenience. Whereas co-morbid conditions were cited by informants as the source of ongoing concerns. Informants chronicled challenges with monitoring glucose levels to manage diabetes, or reducing stress and adjusting medication to address concerns with hypertension.

Warren-Jeanpiere, Dillaway, Hamilton, Young, and Goparaju (2014), in exploring the effects of co-morbid diseases on the lives of aging HIV-positive African American women, examined how factors such as age identity, social responsibilities and relationship status affected their ability to manage their conditions. One of the themes researchers extracted using IPA was “daily life struggles,” which detailed, in part, how HIV and aging were not always the most important concerns for African American women. Their participants listed diseases such as diabetes and hypertension as significant sources of distress. This finding is consistent with what was reported by informants of the current study; just under half of whom were older African American females. Additionally, participants of the Warren-Jeanpiere et al. (2014) study and informants of the current study remarked that co-morbid conditions required more mental effort to manage. They theorized that the success of anti-retroviral therapy and the expectation of a normal lifespan may contribute to women’s less negative focus on aging and HIV. Nevertheless, as older HIV-positive African Americans through the advent of anti-retroviral therapy are living longer lives, they still must have their co-morbid condition(s) treated concurrently with HIV in order to achieve optimal health outcomes (Justice, 2006).

Although the current study and the Warren-Jeanpiere et al. (2014) study are similar, distinct differences lie at the heart of these two studies. Whereas the researchers did not include any older African American men in their study design, the current study was gender inclusive, specifically seeking both men and women, in looking to understand the lived experiences of older HIV-positive African American adults. Also, the inquiries of their study were narrowly focused around a person’s ability to self-manage their

conditions. Beyond understanding how they self-manage their HIV and co-morbidities, the current study was seeking to more deeply understand how older African Americans experienced HIV and age-related diseases. By contrast Warren-Jeanpiere et al. (2014) were focused on understanding how female participants self-manage their HIV condition, given their social responsibility, age, and relationship status, rather than their lived experiences with HIV and co-morbid conditions.

Almost all of the men described experiences where they encountered some kind of HIV-related trauma that affected their ability to trust. Trauma included both living with the disease as well as experiences connected to having HIV. Of note, all of the adults in this study commented about stigmas that they feared. However, it was the men whose experiences translated to trust issues. Negative encounters with friends and families, the medical community, and other HIV-infected peers, around keeping confidences resulted in male informants expressing deep concern of being outed, stigmatized, and even experiencing violence. They asserted that these issues sometimes caused extreme anger, withdrawal, and social isolation, which resulted in attitudes of suspicion, circumspection, and mistrust. Perhaps the male informants' mistrust is attributed to their struggle with internalized stigma, and by holding negative beliefs about themselves because of HIV, expected others to treat them with contempt and hostility.

Informant Mark angrily recounted an experience with a medical provider where confidentiality regarding his serostatus was not respected. He remarked that he left the hospital shortly after the traumatic event without receiving the treatment that was needed. Such issues around trust can become extremely critical when older HIV-positive African Americans do not engage with their medical providers. Mistrust of the medical

community can presage poor HIV treatment adherence and negative medical outcomes (e.g., HIV-related morbidity and mortality; Earl et al., 2013). An individual's trust in medical institutions often is associated with the cultural competency of care providers (Whaley, 2001). In the incident Mark described, medical providers showed poor ethical judgement in publicly discussing a patient's records, and displayed poor cultural competency in failing to consider the possible stigma that the patient could encounter as a result of the hospital's public disclosure (Earl et al., 2013). In their study of 450 African American patients' trust in their medical providers, Earl et al. (2013) asserted that trust in the medical institution and cultural similarities were closely associated with the patients' trust in medical providers. One of the keys for how a medical provider can effectively interact with African American patients, is to understand how they experience stigma.

Overstreet, Earnshaw, and Kalichman (2013), in their study of internalized stigma among 156 African American HIV-positive men who have sex with men, shared that because these men are socially devalued on the basis of their HIV status, sexuality, and race, they internalize the negative stigmas associated with those identities. Such internalized stigma can lead to disengagement from friends, family and significant others, and specifically on the issue of disclosing HIV status. The higher the internalized stigma for African American men who have sex with men, the less likely that they would disclose HIV status to family members and partners/spouses, and the more closely and diligently they will guard this secret. Overstreet et al. (2013) noted that the participants of their study also experienced co-occurring stigmatized identities. Although in-depth discussion of co-occurring stigmatized identities were not the focus of the Overstreet et al. (2013) study, they are consistent with what the male informants of the current study



reported experiencing. For example, Mikey commented that "...society has been taught the wrong things about people with HIV...so you see a lot of people getting beat down, beat up, or getting shot behind this." An inference from this extract is that Mikey who does not identify as gay speaks about the misinformation that persists and provokes people within his community to have hostility toward men who are perceived as being HIV-infected homosexuals, and act violently towards them. While only a few male members of this study identified as gay or as men who have sex with other men, many of the males in this study reported struggling with stigma related issues, including co-occurring stigmas.

To address stigma and other psychosocial stressors and explore coping strategies for HIV-infected adults, Martin, Vosvick, & Riggs (2012) examined how attachment style and forgiveness affect the quality of life for adults living with HIV. They recruited and assessed 288 HIV-infected people. Participants of their study completed a variety of assessments that included measures of attachment, forgiveness, and quality of life scales. Results revealed that the higher the attachment anxiety, the lower the quality of life. But for anxiously attached persons, forgiveness of self, even more than forgiveness of others, was positively associated with improved feelings. Forgiving self for past mistakes, the authors asserted, when attachment anxiety is high, correlates to positive physical and mental health outcomes, and better quality of life.

In the current study, several of the male informants appeared to be more anxiously attached. Informant Mikey asserted that even as he would "isolate myself from everybody," that that was something he did not want to do. Mark commented that when visiting some doctors' offices for his HIV-related care, "[I would] get the feeling they

don't really want you there." In the context of the present study forgiveness of self might be a possible intervention for stigma. As a coping strategy forgiveness of self enables a person to release some of the psychosocial based stress, including internalized stigma.

## **II. HIV spurs self-advocacy**

As this study's informants begin to acclimatize to living with HIV and age-related co-morbidities, they began to exert efforts to improve the quality of their lives. All of them reported exploring relationships as a way to enhance well-being, with some sharing experiences of struggling with personal relationships. Informants discussed reaching out to family, re-establishing broken ties, and seeking out social networks of persons with similar experiences. Many derived emotional sustenance from social support. Supportive relationships with significant others, friends, and family enabled informants to endure the difficulty of HIV/AIDS (Mosack, Stevens, Brouwer, & Wendorf, 2016). Social support is frequently divided into three components: instrumental, informational, and emotional (Heaney & Israel, 1997; Kelly, Hartman, Graham, Kallen, & Giordano, 2014).

Instrumental support includes tangible support (e.g., driving someone to their medical appointment); Informational support includes transferring medical and cultural information via verbal or written communication, and Emotional support includes empathic listening, sharing positive feedback, and discussing problems. Informants shared how emotional support, in comparison to the other forms of support, was very important in helping them to manage their illness. Ruth commented that having someone she can reach out to when distressed helped to free her mind. Alva mentioned happiness in re-connecting with her son. Emotional support was associated with higher incidences of a person with HIV advocating for their own well-being (Kelly et al., 2014). Social

support could be provided by medical health professionals (e.g. paid helpers) designated formal support, or informally through family and friends (Edwards, 2006).

In their study to explore and understand how informal social support among HIV+ African Americans and informal social support between infected African Americans and others within the African American is given and accepted, Mosack et al. (2016) conducted interviews of HIV+ individuals in dyads (HIV+ members helping/assisting each other) as well as focus groups. Study findings divided participant accounts into two sets of themes: positive themes where social support helped, and negative themes where social support did not meet needs. Support themes that were viewed as efficacious included communicating interest, taking initiative to help, and making long-term investment. Participants shared how they were helped when friends and family asked questions about health status, or educated themselves, were proactive in working to assist HIV+ member and demonstrated commitment to advocate for the member. This study's findings correlated to positive support experiences reported in the Mosack et al. (2016) study. For example, Mark asserted that his wife and daughter help him to "keep it going" by checking on him, reminding him to adhere to his medication regimen, and admonishing him if he misses a dose. Mark's family has taken the initiative to learn about his illness, and made a commitment to encourage him to keep engaged with his HIV-related medical treatments. Eddie discussed his experience with a support group of other HIV-positive adults which enabled him to share "[what's] going on with me...you know stuff like that I like to get off my chest..." Through the adult support group's commitment to advocate for members, Eddie could use his participation to exchange information and to gain knowledge.

Conversely, the negative themes Mosack et al. (2016) reported included fear of contagion, reticence to be involved, judgment and rejection, and disregard for privacy. Participants commented that needs were unmet when family members' ignorance targeted participants in the form of rejecting behavior, when family members hesitated or refused to become better informed or get involved, when they engaged in judging the participant, and when through unsolicited disclosure of the participant's serostatus, deny participants the prerogative to share their serostatus on their own terms. Mosack et al's (2016) report of negative themes is consistent with the experiences described by informants of this study. For example, rejecting behavior by friends or family was demonstrated when Ruth reported feeling hurt and dismissed when people with whom she was acquainted brushed aside her physical discomforts telling her "you ain't hurtin' that bad." Similarly, Cory reported feeling discouraged for being judged by his fellow HIV-positive male peers because he refused to conform to a certain identity. He commented, "A guy in a position to help...already assumed I was arrogant." In both of the examples, informants characterized the relationships as unhelpful, and demoralizing. For African Americans living with HIV/AIDS, the support of families of origin, or peers can help to foster resilience (Earnshaw et al., 2015). The success and struggles in pursuing relationships contributed to older African Americans developing resilience.

Through resilience, older HIV-positive African American adults living with age-related co-morbidities have found ways to successfully navigate aging and the challenges with illness. Resilience is a person's ability, in conjunction with family and/or community resources, to prevail over health and developmental threats (Earnshaw et al., 2015). Often among society's most vulnerable, older HIV-positive African American

adults living with age-related co-morbidities bear the burden of carrying multiple stigmatized identities (e.g. being Black, older, gay, female, low SES) which are thought to affect health disparities (Earnshaw et al., 2015). Syndemics are defined as one or more co-occurring adverse health conditions that interact synergistically within a specified group (O’Leary, Jemmott, Stevens, Rutledge, & Icard, 2014). Syndemics for the informants of this study might include substance abuse and HIV, or diabetes and HIV. In their study that examined the effects of syndemic conditions on sexual risk behavior and HIV infection within a group of high-risk or HIV-infected African American MSM, the researchers sought to replicate studies that showed how resilience buffered the effects of syndemics. Results indicated that resilient factors did not have much of an effect in reducing HIV sexual risk behavior, but resilience factors such as optimism and education were significant buffers on HIV-infection, and associated with improved HIV-health outcomes (Rasmussen, Scheier, & Greenhouse, 2013).

Although the focus of the O’Leary et al. (2014) study is the African American MSM and HIV sexual risk behavior, the results of that study appear consistent to the experiences described by informants in the present study; which suggest that syndemic conditions might be buffered by resilience. Despite the threat of stigma, health disparities, and psychosocial stressors, informants had resolved to make the best of their conditions. For example, Ruth, as the oldest of this study’s informants, has decided to be more proactive about her health, and accept the limitations of aging. Pepper confronted with HIV and co-morbid conditions whose debilitating effects are medically difficult to distinguish between, resolved to maintain a positive attitude. Ruth’s cheerful disposition and Pepper’s frequent references to “be positive,” echo the resilience factor of optimism.

Resilience factors cited in Earnshaw et al. (2015) that could serve as interventions for mental health providers who work with older adult HIV-positive African Americans include adaptive coping, which incorporates creating and/or finding support groups for people with multiple marginalized identities seeking affirming affiliations, and empowerment, which includes increasing health literacy: culturally-based education about their health and treatment to reduce internalized stigma. Adaptive coping as an intervention may have the additional benefit of enabling older African Americans to advocate for themselves.

### **III. Health as a fragile construct**

All of the women informants in this study remarked about acute experiences of vulnerability which was contributed to by internalized stigma that followed the diagnosis of HIV. Unlike the male informants, who after their diagnosis intentionally isolated and distanced themselves from others, female informants struggled with the idea of loneliness and isolation. The women informants did express some concerns for autonomy, but shared a more visceral fear of a future filled with loneliness. Some of the women expressed grave concern about HIV accelerating the aging in their bodies, and a compromised immune system which could cause the appearance of opportunistic infections. Merle remarked that hearing about diseases in same-aged peers caused her distress because “I’m going to get nervous thinking I’m going to get that, cos I have HIV...” One of the female informants, Debbie, questioned her attractiveness to potential mates, remarking after her diagnosis, “Where can I find me a good man...if I tell them, then they don’t want to be with me.” Besides struggles with economic and social devaluation, African American females infected with HIV can bear the burden of stigmas

that make finding a supportive partner extremely difficult. Questions of how to reveal one's HIV status to a partner who is HIV-negative can seem daunting. Older African American women in their 50s have to contend with societal ageism (Emlet, 2006). Warren-Jeanpiere et al.'s (2014) participant remarks (that became a superordinate theme) were to "forget the single life" and detach from the single-minded pursuit of romantic relationships in order focus on disease management. The understanding among the participants was not to sacrifice one's mental and physical health in pursuit of a supportive romantic partner. Social support among friends, family, and peers was one way participants found to address feelings of loneliness and isolation. For some of the older African American participants, as societal ageism and HIV-related stigma potentially limited their access to financial resources, economic insecurity along with HIV-related stigma made social support especially critical (Heckman et al., 2000).

In their examination of the social support needs for women over the age of 50, Warren-Jeanpiere et al. (2017) conducted five focus groups with 23 HIV-positive African American women who were at least 50 years old. Researchers were interested in the participants' perceptions of aging with HIV and how HIV chronicity (their experiences since being diagnosed when HIV was most fatal) interacts with social support needs. Two of the four themes that study revealed were "The silence is killing us," and "I need something more." Those two themes resonated with the vulnerable experiences reported by informants in the present study.

The theme "The silence is killing us" grew out of participants' frustration and sadness that they wanted to talk to families, friends, and medical professionals about their illness and experiences rather than keeping it inside. In the present study, informant

Debbie shared accounts of crying at night in her bathroom, in part because she was not able to talk about her illnesses with her niece and son. As a woman of Caribbean descent Debbie struggled with concealing her serostatus from people in her community because of HIV-related social stigma. She expressed fear of divulging her status to her child or her niece, who lived with her, and as a result described feeling isolated. Debbie's feeling of loneliness and crying were echoed in her statement, "It's so hard, it's really stressin', it's like...there's no future."

The theme "I need something more" referred to participants commenting that while formal support helped, they needed more. As they aged, their social support needs changed. Over time, their social support needs evolved. For some of the women who had been diagnosed when HIV mortality was at its peak, healthcare providers were standing in as the only source of formal social support. However, as participants survived, their needs have extended beyond clinical services received at the doctor's office. Clinical services met instrumental and informational support needs. In the current study, Ruth's social support system consisted almost entirely of the network of healthcare providers that attended to her illnesses. She reported feeling depressed when she called the clinic to speak with her healthcare provider and was unable to get anyone on the phone. She remarked that at times she felt that no one cared. Ruth's vulnerabilities manifested more from feelings of isolation than from physical discomfort. Alva commented on her ongoing struggles with substance abuse. Maintaining her sobriety, HIV and co-morbid conditions consumed much of her physical and mental energy, and was a constant that had to be negotiated around in her marriage. Although Debbie, Ruth, and Alva were able to manage their illness because healthcare teams attended to their instrumental and



informational support needs, they each expressed greater need for emotional support. Warren-Jeanpiere's (2017) conclusion that emotional support needs "might ebb, and flow, and change throughout women's lives..." even as other social support needs remain constant, (p. 399) appears consistent with the experiences shared by women from this study's informants.

The two remaining themes from the Warren-Jeanpiere et al. (2017) study, "Life begins at 60," and "Stop worrying about everybody else," also had relevance for the informants of the current study. The Warren-Jeanpiere (2017) study and the current study show common issues that may be a way to address clinical concerns for the informant population.

The theme of "Life begins at 60" echoes the refrain from participants who responded to questions about aging wherein they described reaching a point in their identity where they had achieved a sense of comfort about their chronological age, which reflected greater self-acceptance. The remaining theme, "Stop worrying about everybody else," referred to participants learning to place their own needs before others' needs, for the sake of maintaining a healthy life. Participants reported that in their identities as mothers, wives, significant others, and friends, they were seeking more instrumental and emotional informal support from others.

Starting conversations that encourage reframes using the latter two themes, could serve as a mechanism to help older African American women minimize feelings of vulnerability. Learning to derive a sense of comfort with the identity of being older women may help combat the internalized stigma that results from social ageism, and learning to prioritize their own emotional and instrumental support needs, and request

that others help meet those needs as a method for maintaining a healthy life, may help African American women develop a sense their own value.

Informants reported struggling for a period of time with the psychological effects of HIV after diagnosis. Informants described psychosocial and mental health concerns that were a result of the impact of being diagnosed and living with the virus and co-morbid conditions. For this study whose informants were recruited from public healthcare clinics, HIV, co-morbid conditions, and the decline of their bodies from aging were stressors that may have presaged co-morbid mental health issues (Israelski et al., 2007). The stress of Ruth's diagnosis, subsequent health problems, and abandonment by her significant other left her struggling to manage her illnesses alone and fueled her depression and descent into cocaine addiction. Debbie described the experience of depressing episodes, Roosevelt reported profound feelings of loneliness and distress, and Cory referred to HIV as a "chunk" in his life after the trauma of diagnosis. The effects of stressful life experiences and trauma (e.g. verbal and physical violence) are linked to negative health outcomes (Zierler et al., 2000).

In their study of 611 mostly African American persons from five southern states, Reif et al. (2011) examined how traumatic and stressful experiences affect people living with HIV/AIDS. Both frequency and type of trauma/stressful events were assessed including relationship difficulties, death/serious illness of important people in participants' life, non-HIV related injuries/illnesses, and major life transitions, to name a few. Results indicated that substance use and mental health were associated with participants who reported more stressful experiences, and that high levels of stress can have a negative impact on the quality of life. Researchers noted that incident stress (e.g.,

financial difficulty, non-HIV related injury/illness) can be addressed if support services such as case management are utilized to address client concerns. Also, mental health services such as group and/or dyadic therapy to target substance abuse could help provide support to manage stress and alleviate the effects of trauma.

The substance use and mental health challenges in the Reif et al. (2011) study were reflected in the narratives of informants of the current study. Moreover, informants in the present study shared that the mental health support that they received at local community clinics helped to ameliorate some of the stressful experiences of living with HIV. Similar to some of the experiences discussed by participants in the Reif et al. (2011) study, this study's informants had to process HIV-related trauma. For example, several informants discussed the suicide of one of the other older HIV positive peers, and how it impacted them.

While most of this study's informants mentioned that they benefited from the dyadic and group therapies offered at community clinics, expanding on the Reif et al. (2011) study to explore how stress and trauma specifically affect HIV-positive African American adults who are simultaneously aging with HIV and age-related co-morbid conditions may inform more targeted and better informed interventions.

One of the areas that was of most prominent concerns for HIV-positive older African American adults living with co-morbid conditions was the fragile and sometimes capricious nature of their health. Co-morbidities often worked synergistically with HIV to manifest adverse health conditions and increase informant distress. Informants reported grave concerns with diabetes whose health effects were made worse by HIV, with both diseases posing significant health concerns to the immune and vascular systems (Zuniga,

Nguyen, & Holstad, 2016). For example, Mikey described struggling with glaucoma and seizures related to regulating his food intake, explaining that if he ate too little or too much glucose he could slip into a diabetic coma. Missteps in managing the delicate balance of eating the right foods have left Mikey struggling with HIV and diabetes-related co-morbidities, and compromised health.

The combination of HIV drugs in ART have proven to be successful in stopping the virus, but can induce painful peripheral neuropathy in patients (Dalakan, 2001). The pain and discomfort experienced in the extremities of the body from neuropathy, can dramatically affect the quality of life for some of those afflicted enough to necessitate discontinuing the HIV medication (Dieterich, 2003; Johnson & Folkman, 2004). For example, Ruth described numbness in her feet that caused her to express concern about falling and injuring herself. Eddie characterized his neuropathy as “thunder and lightning through your legs...you’re walking on a nerve” and was often seen walking with a cane. Participants’ experience of neuropathy could be sufficiently debilitating to impair their ability to perform basic life tasks.

Their struggles were exacerbated by medication regimens that resulted in high pill counts, adverse physical and psychological reactions to medicine toxicity, and associated depression over the prospect of a lifetime of mandatory medication adherence. A commonly shared complaint among informants was pill fatigue. Alva reported how the sheer number of pills increased with every co-morbidity for which she was diagnosed. Cory reported feeling nausea and dizziness each morning with his daily dosage of medication. Debbie commented about the confusing and complicated regimen of understanding how to take which pill for which condition at which time of day as

prescribed. Informants shared that because of the challenges of medication adherence for multiple conditions, they considered taking or actually took pill holidays. Quality of life became a significant factor to consider when commencing or continuing adherence to ART (Buseh, Kelber, Stevens, & Park, 2008).

In their exploration of the relationship of symptom prevalence, intensity, perception of health, and stigma, to quality of life for HIV-positive African American men, Buseh et al. (2008) recruited 55 African American MSM and assessed them for HIV and co-morbid symptoms experienced including intensity and impact of the symptoms, stigma, perceived health, and demographic characteristics. Participants in this study reported a variety of different symptoms that depending on their severity contributed to low perceived health and diminished quality of life. For this study and for its participants, stigma was a major contributing factor to a person's overall perception of health and quality of life. An inverse relationship was reported for perceived health, where disease progression and stigma were high, participants reported feeling poorly. Researchers found that disease progression alone was not associated with low quality of life, whether the participant was asymptomatic, symptomatic, or had full-blown AIDS. Stigma, certain sociodemographic qualities (e.g., limited education, low SES, housing issues) and symptomatology contributed to quality of life concerns.

Although the findings of the Buseh et al. (2008) study were specifically about the experiences of African American MSM, the results reported by its participants appear consistent to similar health concerns raised by informants of this study. Debbie shared how difficult it was for her to self-manage the disease. Keeping her serostatus a secret from her family because of internalized stigma deprived her of a possible support

network. She talked about the challenging medication regimen and her sub-optimal health. Her quality of life was reflected in the description of her life managing her illnesses: “It’s hard, very hard.” The syndemic relationship of Mikey’s HIV and diabetes forced him to be very vigilant about his health. Mikey’s internalized stigma caused him to be mistrustful of others and keep people at arm’s-length, even as he commented that he did not want to keep people distant. Mikey’s health complications and his reluctance to trust others suggested a limited support network and low quality of life.

Buseh et al. (2008) suggested in their findings that addressing symptoms were critical in long-term HIV treatment, but not alone sufficient to advance quality of life concerns. To improve quality of life for African American MSM, the authors suggested that both symptomology and social stigma must be examined and treated. The results from their study included one noteworthy finding indicating that the presence of education created an inverse relationship with perceived stigma for participants. The higher the education the lower the perceived social stigma.

Regarding the present study, this author noted that informants mentioned that they felt better about their illnesses when they educated themselves. Shortly after diagnosis Merle described going to the library to read up on her diseases. It was there that she learned that she acquired HIV from a hospital treatment for anemia, and not from a sexual encounter. She commented that she copes in part by learning as much as she can about her conditions. Many of the other informants commented that learning about their conditions helped give them a sense of agency and denuded some of the HIV-related stigma (Earnshaw et al., 2015).

In light of the experiences described by informants regarding stigma and symptomology, further study of how those factors impact quality of life and possibly affect interventions, could inform current research and best practices for older African Americans living with HIV and a co-morbid condition.

**Summary of clinical implications.** Embedded within the three super-ordinate themes was the notion that aging, navigating comorbidities, and surviving with HIV and/or AIDS were inextricably intertwined, and how informants psychologically and physiologically experienced their conditions. Of their experiences, the two main areas upon which the literature and this study converge—internalized stigma and the lack of informal support—represented some of the most significant informant concerns. Internalized stigma can create serious psychological distress and concomitant mental health concerns. Informants, particularly the men, struggled with negative beliefs about themselves because they have HIV (Herek, 1999). Negative self-perceptions that created attitudes of suspicion and mistrust, even towards family and friends, which led to some of the men denying themselves access to the informal social support that they needed. Similarly, informants, particularly the women, struggled with the need for informal social support. Informal social support included instrumental (e.g., help with managing meds), informational (e.g., increasing health literacy), and emotional support that was provided by nonprofessional significant people in the patient's life. Of the three areas of support, lack of emotional support was mentioned by informants and various studies as being the psychostressor that affected people the most.

By exploring internalized stigma and informal emotional social support needs of older HIV-positive African Americans living with co-morbid conditions, psychologists

and other HIV-related health providers can unearth a wealth of information connected to relationship dynamics, social behavior, medication adherence, and mental health (Vella, 2015). From this information, interventions that are meaningful may be created that can increase and enhance the quality of life for older HIV-positive African American adults living with co-morbid conditions. Some intervention suggestions include: exploring the therapeutic idea of self-forgiveness to combat negative internal feelings attributed to internalized stigma, providing HIV and medical care teams with culturally sensitive information about the reality of HIV-related stigma and homophobia experienced by older HIV-positive African American men to allay trust concerns that some African Americans harbor toward healthcare providers, and enlisting the collaboration of peers, family, friends and significant others to act as an informal emotional support system to help address the evolving emotional support needs of aging African American adults. The study results underscore the need for researchers to initiate quantitative and qualitative work that include the experiences of older HIV-positive African Americans living with co-morbid conditions. Qualitative research on the experiences of HIV and co-morbid conditions on younger African American MSM, on HIV-positive younger women, and other marginalized groups will enable these groups to have a voice in the creation of HIV-related patient-centered care.

### **Limitations, Strengths, and Conclusion**

IPA focuses its gaze on the particular. Idiography seeks to know in detail the nature of an experience for *this* particular person, and how *this* person makes sense of what they are experiencing (Smith et al., 2013). Because the researcher must make sense of an experience the participant makes sense of, IPA is relational. IPA functions as the



antithesis of quantitatively-based research in that it tries to remedy underexplored relational and social-discursive theories (Larkin et al., 2006). Ultimately, IPA is oriented toward the world of the individual in that person's environmental context which provides the opportunity to reflect and advance toward the universal (Vella, 2015; Smith et al., 2013). This study explored the lived experiences for ten HIV-positive older adult African Americans using interpretative phenomenological analysis. Using purposeful and snowball sampling, informants were recruited and selected based on the criteria of race, age, HIV status, having age-related co-morbidities, and the ability to speak and read English. The informants of this study all came from a clinic, or were referred to this study from other clinics that served a population of HIV-infected low income people of color from a large metropolitan area. Although these clinics served other racial/ethnic groups and young people of color, this study's race and age requirements precluded their involvement in this study. Also, this researcher was unable to locate more female informants in order to have gender parity within the sample set. The disproportionate number of people in the African American community who have or transmit HIV are men, specifically MSM (Prejean et al., 2011; Peterson & Jones, 2009); hence, the pool of potential recruits among men was larger. This researcher was unable to locate transgender informants for this study.

The experience of living with HIV and a co-morbid condition may not be the same for older African Americans who identify as transgender. Transwomen of color have much higher odds of contracting HIV than other groups, and have to endure significant amounts of stigma, poverty, violence, and structural barriers (Sevelius, Patouhas, Keatley, & Johnson, 2014). Because of psychosocial stressors usually related

to transphobia, limited access to transition-related healthcare, and lack of gender-affirming HIV healthcare, transwomen of color often are not retained in HIV-medical care, have poorer health outcomes, and higher rates of mortality (Sevelius et al., 2014). Considering the multiple stigmatized identities, unique healthcare needs, the presence of aging, HIV, and the possibility of co-morbid conditions in older transwomen of color, fertile ground exists for qualitative research that could expand understanding of their lived experiences.

The researcher attempted to suspend existing knowledge, which would enable him to view the world as experienced by the informants, thus enacting the phenomenological aspect of analysis (Larkin et al., 2006). The small, specific, homogeneous sample of informants provided the narratives that helped to contextualize their experiences. This study was based on their accounts. Missing from informants' accounts were potentially confounding factors that may have affected how they viewed their experiences (e.g., systemic racism, Ryan White Care as social safety net; Vella, 2015). Informants recruited to this study came from a large metropolitan area and have access to many conveniently located HIV-related social service agencies and medical clinics. Had they lived in rural areas and poor communities they may have reported different lived experiences. Additionally, informants in this study were seeking care on a regular basis at a community clinic, and were benefiting from the wrap-around services (e.g., housing, mental health, dental, medical, food), neither of which are necessarily available to older HIV-positive African Americans living in other communities.

Much of the research on adults with HIV addresses HIV and aging from a chronological and biological perspective, and neglects the social, cultural, and behavioral

components that affect older lives and how that information might guide their course and treatment choices (Sankar et al., 2011). Most of the research of a qualitative nature that explores the lives of African Americans and HIV pertains to the experiences of MSM, young adults, and heterosexual women (Wilson et al., 2016; Dillon & Basu, 2014; Crepaz et al., 2009; Smith et al., 2012). A significant portion is devoted to addressing HIV sexual risk and prevention efforts for MSM. (Bowleg, 2011). Underreported in the literature are studies on the lives of older African Americans and the effects of HIV. To the best of the author's knowledge, this is the only study to explore the lived experiences of older HIV-positive African Americans living with age-related co-morbidities.

Because this is an IPA design study, the sample set is deliberately small and the findings are not aimed at extrapolating to other populations (Smith et al., 2013). Further research would benefit from exploring how the themes of this study may apply to other African American groups living with HIV and a co-morbidity. Additionally, qualitative and quantitative research that focuses on understanding and addressing the unique concerns of older African Americans living with HIV and co-morbid conditions could serve to reduce health disparities (Yancey, Ortega, & Kumanyika, 2006).

Michelle Yella (2015) in her IPA study of body image experiences among HIV-infected heterosexual racial/ethnic minority males, noted that specific factors (i.e., invisibility, stigma, disenfranchisement) made accessing and recruiting that population challenging. Similarly, for the current study, because of psychosocial stressors such as HIV stigma, ageism, homophobia, and racism, researchers or clinicians desiring contact with older HIV-positive African Americans will want to have cultural familiarity with this population, a connection to the HIV community and/or HIV-specific healthcare

training. One of the strengths of this study is an in depth focus on the lived experiences of older HIV-positive African Americans. Similarly, much of the thought that informed this author's interpretations of informants' experiences is grounded in five years of clinical service to the HIV-infected African American community, and extensive interaction with the older clients within that population. Such interaction enabled the researcher to have some sense of the embodied experiences of aging with HIV and age-related diseases, the psychological stress, and the emotional toll that older African Americans endure day-to-day.

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**Table 1****Demographic statistics**

<u>Race</u>	African American	100%
<u>Gender</u>	Male (n=6)	60%
	Female (n=4)	40%
<u>Age range</u>	(51-72)	mean age 57.6; SD 6.738
<u>Education</u>		
	Middle/junior high school	(n=1) 10%
	High school	(n=4) 40%
	College	(n=5) 50%
<u>Sexual Orientation</u>		
	Heterosexual	(n=7) 70%
	“Fluid” (male or female)	(n=1) 10%
	Bisexual	(n=1) 10%
	None identified	(n=1) 10%
<u>Co-morbid conditions</u>		
	Neuropathy	(n=5) 50%
	Cancer	(n=2) 20%
	Hypertension	(n=6) 60%
	Arthritis	(n=3) 30%
	Diabetes type II	(n=2) 20%
	COPD	(n=1) 10%
	Congestive Heart Failure	(n=1) 10%

Table 1, continued Characteristic Participants (n = 10) (Diagnosed = Dx)

“Merle”	Dx 1997	PLWH 19 years
“Alva”	Dx 2009	PLWH 7 years
“Pepper”	Dx 1995	PLWH 21 years
“Eddie”	Dx 1999	PLWH 17 years
“Debbie”	Dx 1997	PLWH 19 years
“Mikey”	Dx 1991	PLWH 25 years
“Ruth”	Dx 1997	PLWH 19 years
“Roosevelt”	Dx 1989	PLWH 27 years
“Mark”	Dx 1989	PLWH 27 years
“Cory”	Dx 1989	PLWH 27 years
( <i>n</i> =10)	7-26 years	Mean years 20.8

**Appendix A****Informed Consent Form**

Antioch University Santa Barbara (AUSB)

Department of Psychology (2015)

Informed Consent for Participants

Study Name: HIV and life-course diseases in older African Americans

Principal Investigator: James Chavers

Faculty Supervisor: Steve Kadin, PhD

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**PLEASE READ THIS DOCUMENT CAREFULLY. YOUR SIGNATURE IS REQUIRED FOR PARTICIPATION. YOU MUST BE AT LEAST 18 YEARS OF AGE TO GIVE YOUR CONSENT TO PARTICIPATE IN RESEARCH. IF YOU DESIRE A COPY OF THIS CONSENT FORM, YOU MAY REQUEST ONE AND WE WILL PROVIDE IT.**

The policy of the Department of Psychology is that all research participation in the Department is voluntary, and you have the right to withdraw at any time, without prejudice, should you object to the nature of the research. You are entitled to ask questions and to receive an explanation after your participation.

Description of the Study:

This is a single session study (with the possibility of a follow-up) in which an interview will be conducted, and a demographic questionnaire will be used. To do this, we will ask you to do the following: answer ten questions in a semi-structured interview that may

last 60-90 minutes (which will be digitally recorded), and provide some basic demographic information (i.e. age, race, gender, HIV status, education, sexual orientation, and age-related disease).

#### Nature of Participation:

You will participate in a single session. In the session you will: fill out the demographic questionnaire, and answer the interview questions. If there is a need for a follow-up you will be contacted and asked to participate in an additional session. In the (second) session the researcher may meet with the participant to follow-up and see if a preliminary report of the interview data truthfully and accurately reflects the participants' experience.

#### Purpose of the Study:

To have older African Americans share their perceptions, feelings, and experiences of living with HIV and an age-related disease. In order to advocate for and effectively provide treatment to this population, the intent of this study is to understand the lived experiences of older African Americans living with HIV and age-related diseases.

#### Possible Risks:

- a) When filling out the demographic questionnaire, or answering questions in the interview you may (come across a question or answer choice) that you find unpleasant, upsetting, or otherwise objectionable. For instance, (a few of the questions may cause you to think about negative emotional states.)
- b) You may feel that you have performed poorly on a survey. For many of the activities, the survey and questionnaire we are evaluating, there is no right or wrong answers. This study is interested in what is true for you.

We encourage you to discuss this with the interviewer during the debriefing period, when all procedures have finished.

c) You will be asked to provide confidential information about yourself.

Possible Benefits:

a) When your participation is complete, you will be given an opportunity to learn about this

research; which may be useful to you in understanding yourself and others.

b) You will have an opportunity to contribute to psychological science by participating in this study.

Compensation for your Time:

You will receive a ten (\$10) gift card to Subway restaurant for completing the interview.

You are free to withdraw your participation at any time without penalty.

Confidentiality:

You will be assigned a code number which will protect your identity. All data will be kept in secured files, in accord with the standards of the University, Federal regulations, and the American Psychological Association. All identifying information will be removed from questionnaires, and interview transcripts as soon as your participation is complete. No one other than the interviewer and the dissertation committee will be able to know which are your questionnaire/interview responses. Finally, please understand that if you should before, during or after the interview express to the researcher the intent to harm yourself, or do harm to another, this researcher will need to break confidentiality to protect you or someone you may intend to harm.



### Opportunities to Question:

Any technical questions about this research may be directed to:

Principal Investigator: James Chavers Phone: xxx-xxx-xxxx

Any questions regarding your rights as a research participant or research-related injuries may be directed to: Xxxxx Xxxxx, PhD. xxxxxx@antioch.edu (xxx) xxx-xxxx AUSBs Institutional Review Board (IRB) (xxx) xxx-xxxx

### Opportunities to Withdraw at will:

If you decide now or at any point to withdraw this consent or stop participating, you are free to do so at no penalty to yourself. You are free to skip specific questions and continue participating at no penalty.

### Opportunities to be Informed of Results:

In all likelihood, the results will be fully available around \_\_\_\_\_ (date).

### Preliminary

results will be available earlier. If you wish to be told the results of this research, please contact:

Principal Investigator: James Chavers\_\_\_\_\_ Phone: xxx-xxx-xxxx\_\_\_\_\_

He will either meet with you or direct you to where you can read a copy of the results. In addition, there is a chance that the results from this study will be published in a scientific psychology journal, which would be available in many libraries. In such an article, participants

would not be identified by name.

Your signature below indicates that you voluntarily agree to participate in this study.

Dated this \_\_\_\_\_ day of (month) \_\_\_\_\_, 20 \_\_\_\_

\_\_\_\_\_

Signature of Participant

\_\_\_\_\_

Signature of Person Obtaining Consent

**Appendix B****Demographic Questionnaire**

Please take a moment and fill in your answer in the blank.

A. Race: \_\_\_\_\_

B. Gender: \_\_\_\_\_

C. Age: \_\_\_\_\_

D. Education \_\_\_\_\_

E. Sexual Orientation \_\_\_\_\_

F. Disease(s) (other than HIV) \_\_\_\_\_

\_\_\_\_\_

**Appendix C**

- 1) Describe your day-to-day experience of living with HIV and an age-related disease.
- 2) Since you found out that you have \_\_\_\_\_ along with HIV describe your feelings throughout the day (for example, at the time of day when you take your HIV meds and/or \_\_\_\_\_ meds).
- 3) When thinking about the future, describe what you think it looks like for you.
- 4) Tell me about the support system you use to help you get through the day, and why you use it.
- 5) What barriers do you encounter, socially, or personally, that stop you from feeling better? Please describe them.
- 6) What DOES help you feel better? Please describe it.
- 7) Tell me about some of the ways you cope with your condition.
- 8) As an African American describe what HIV and \_\_\_\_\_ is to you, and why do you think that you have it/them?
- 9) If or when you feel distress about these multiple diseases, how could a mental health professional help you to feel better?
- 10) When did you find out you were positive, and that you had \_\_\_\_\_? How have your feelings changed since then?

## **Appendix D**

### **HIV and life course diseases in older African Americans**

#### **Research Study**

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Are you at least 50 years old, African American, and living with HIV?

Are you currently living with any age-related diseases (cancer, diabetes, hypertension, etc)

If yes, you may be eligible to participate in a research study looking at the effects of HIV and an age-related disease on the lives of older African Americans

If you qualify, you will be asked to participate in one interview. You may be asked to participate in a follow-up interview.

You will receive a \$10 subway gift certificate for each completed interview.

**We travel to you!**

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For more information on this study, please contact James Chavers of Antioch University Santa Barbara PsyD Program at (626) 487-7609